My Support My Choice:

People's Experiences of Self-directed Support and Social Care in Scottish Borders

August 2021

Self Directed Support Scotland
the organisation of choice

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people at the centre

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Acknowledgements and Dedication

This report is published with thanks to the people who shared their experiences and facilitated the research in Scottish Borders. It is dedicated to members of the research team and those who shared their experiences as participants who have since passed away.

About this Report

This report uses data[1] from "My Support, My Choice: User Experiences of Self-directed Support and Social Care in Scotland" (MSMC), a research project run by the Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), funded by the Scottish Government. Focused on people's experiences in Scottish Borders, the report starts by broadly setting out the national and local context for Self-directed Support (SDS) and social care, followed by information about the participants.[2] Subsequent chapters explore people's experiences of SDS/ social care across Scottish Borders. Key findings are highlighted throughout, with a separate chapter on recommendations. The report concludes with a response to the research from Scottish Borders Council and Health and Social Care Partnership.

The document is part of a suite of MSMC reports that also contains a national report, other local authority area reports, and thematic reports, which are published separately.[3]

COVID-19

Data collection ran from 1 November 2018 to 14 February 2020. As such, all responses reflect people's experiences of SDS/ social care before the appearance of COVID-19 in Scotland and people's experiences during the pandemic are not covered by the MSMC project.

Nevertheless, this research represents the most recent and comprehensive reflection of people's experiences of SDS/ social care in Scotland prior to COVID-19. As such, MSMC provides vital evidence, analysis of good practice and recommendations for improvement in the review and reform of SDS/ social care in the aftermath of COVID-19, based on people's experiences.

Executive Summary

This report uses data from "My Support, My Choice: User Experiences of Self-directed Support and Social Care in Scotland" (MSMC), a mixed-methods research project run by the Health and Social Care Alliance Scotland and Self Directed Support Scotland, funded by the Scottish Government.

The aim of this research is to gain a better understanding of people's experiences in Scottish Borders, filling a data gap and complementing the work of other independent evaluations. By highlighting evidence of good practice and where improvements can be made, we can assist strategic planning and delivery of future SDS/ social care.

Between November 2018 and February 2020, MSMC heard from 71 people in Scottish Borders who received SDS (or had been assessed in the previous 12 months) via a survey and interviews. Research took place prior to the appearance COVID-19 in Scotland. Overall, MSMC heard from 637 people across Scotland via a survey, interviews and focus groups. As the largest direct national consultation of its kind to date, the national report provides vital evidence, analysis and recommendations for improvement to SDS/ social care in the aftermath of the pandemic, based on people's experiences. This report provides analysis of the results from Scottish Borders within that larger context.

Research participants in Scottish Borders acknowledged SDS as important to achieving a higher quality of life and independent living, and reported positive experiences across several aspects. However, there are some key improvements that would respond to people's concerns, build on existing good practice, and increase the effectiveness and reach of positive SDS/ social care experiences. The views expressed by research participants and analysis of the findings have led to a number of recommendations, many of which echo other independent reviews of SDS.[4]

Poverty and SDS

An estimated 24% of Scottish households with a disabled person live in relative poverty after housing costs. MSMC found that 57% of research respondents in Scottish Borders who provided income data lived below the poverty threshold. National and local public bodies should take action to ensure that reductions in SDS budgets and tightened eligibility criteria do not negatively impact people on low incomes who access or are trying to access social care, given that they can lead to people having to manage without support, deteriorating physical and mental health, and demands on family and friends to assume roles as unpaid carers.

Data Gathering and Analysis

There are concerning gaps in national and regional SDS data gathering and analysis. Disaggregated data and intersectional analysis by local and national public bodies is essential to develop policy and practice that prioritises equal access to social care for everyone, following human rights principles of equality, non-discrimination, participation and inclusion.

Overall Experiences of SDS

Most participants in Scottish Borders reported that SDS had improved their social care experience and shared a range of positive and negative feedback when asked to summarise their experiences.

Information About SDS

Participants in Scottish Borders found out about SDS from a range of sources, and most reported positive experiences. Most people highlighted the value of face-to-face communication with social work, and recommended that those wanting to know more about SDS should get in touch with social work, independent advocacy and independent advice services as soon as possible.

Many participants indicated they required more high-quality information at an earlier stage (before needs assessments) to support their decision making about how support would be arranged. Many people had not been told about all four options when they started the process of accessing SDS. Some had not been provided with accessible information or documentation, even after requesting it from social work.

This pattern of variable information about the four options continued into people's needs assessments. A minority of people reported that they had "all four options" discussed with them during their assessments.

Half of the respondents in Scottish Borders indicated that they had received information about how much money they could spend on their care and support. However, the remaining half had either not received that information or were unsure.

Recommendations include ensuring people have good access to high quality information about SDS/ social care, in a range of accessible and tailored formats at different points in their journey through the system. In general, work is needed to ensure everyone is informed about all four SDS options, and supported to consider the advantages and disadvantages of each SDS option before making decisions – rather than being given information about a more limited list of options. Measures should also be taken to ensure that people are given full and accessible information about their budgets and other relevant financial information.

Informed Choice and Control

Overall, most participants in Scottish Borders felt they had enough time to choose their SDS option. People reported variable wait times for assessments and those who waited the longest also generally reported the highest levels of stress and difficulty in accessing SDS.

A large majority of respondents in Scottish Borders indicated that they are on their preferred SDS option and felt involved in decisions and arrangements about their care and support. While this is very encouraging, the finding that more than a third had their SDS option chosen for them by a health or social work professional – rather than choosing themselves – is more problematic. Professionals play an important role in supporting access to appropriate services; however, this should not extend to making decisions on people's behalf while the principles of choice and control are clearly embedded in SDS policy.

Similarly, while it is positive that most respondents in Scottish Borders were offered the choice of who would manage their personal budget, it is concerning that just under a fifth of people reported being offered no choice, and a further fifth were unsure; this also demonstrates that, amongst other things, they were not fully offered all four SDS options.

Most people indicated that having sufficient budget to meet their outcomes made SDS easier for them – and highlighted the importance of providing support for social activities as well as personal care to ensure a good quality of life. People who used SDS budgets to access short breaks described them as benefiting both individuals and their families – an important chance for people to relax.

Budgets and waiting times were prevailing themes when respondents discussed ongoing concerns with their needs assessments. Reductions to budgets and support has significant negative impacts on people's mental and physical health. Any proposed reductions in SDS budgets or support should be communicated clearly and discussed with people well in advance of any changes being introduced. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

Several people in Scottish Borders highlighted the positive impact of flexible support and SDS. This flexibility could be in how people are empowered and supported to use their SDS, but also related to people's ability to have ongoing conversations with social work professionals and adjust systems accordingly on a regular basis.

Participants – particularly those living in more rural areas of Scottish Borders and those who are blind or partially sighted – indicated that they need more acknowledgement and accommodation of travel costs in their SDS budgets (particularly when it came to having choice of care providers). Some would also welcome assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.

Recommendations include providing social work professionals with training in supported decision making, and targeted efforts to ensure that all people enjoy equal decision making about their SDS option and support.

Communication and Relationships with Social Work

Participants in Scottish Borders highlighted that good, consistent, trusting relationships with social workers and clear lines of communication are all essential for positive and effective experiences of SDS. A substantial majority of participants reported positive and favourable experiences of assessments and reviews with professionals, providing a range of good practice examples. However, some people outlined concerns about not receiving full answers to questions raised during assessments and a small number of participants shared troubling stories of being treated with disrespect by professionals.

Several people raised the need for greater transparency about how care decisions are made and by whom, alongside inclusive communication and easy access to information. Some people reported difficulty obtaining paperwork and documentation concerning their care arrangements, even after repeated requests to social work departments.

Recommendations include ensuring that social workers have the time and skills to build relationships and trust with the people accessing SDS and unpaid carers that they are working with, building on existing good practice in Scottish Borders. People should be informed promptly if their social worker changes and have a right to request a new social worker if trust breaks down. More work is needed to improve the transparency of process – including around how decisions are made about budgets and accessing SDS.

Care Staff Recruitment, Training and Quality

People generally reported good experiences of support worker recruitment, training and quality. Several respondents indicated difficulties finding and retaining personal assistants (PAs) and care workers that were suitable for their requirements, and some people would welcome more assistance with staff recruitment and training. Scottish Borders Council should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality.

Independent Advocacy and Support

Respondents in Scottish Borders value and benefit from the provision of independent advocacy, independent advice and support services, which need sustainable resourcing to continue their important role. Focused efforts are required to ensure all people are aware of, and can access, independent advocacy and support services. Local peer networks should also be encouraged and supported. Encompass and the SDS Borders Forum were mentioned several times as helpful in supporting people to navigate and access SDS.

Recommendations

People in Scottish Borders generally reported that SDS had improved their social care experience and have shared examples of good practice from across the region, particularly about good conversations and relationships with social work professionals, and involvement in care decisions. However, as this research highlights, there are key areas where improvements could be made to respond to people’s concerns, build on existing good practice, and increase the effectiveness and reach of positive SDS experiences. The recommendations in the MSMC national and thematic reports would also usefully inform practice in Scottish Borders.[5]

Poverty and SDS

1. Action is required by national and local public bodies to ensure that SDS budget cuts and tightened eligibility criteria do not negatively affect the physical and mental health of people on low incomes who access or are applying for SDS/ social care.

Data Gathering and Analysis

2. There is a pressing need for local and national public bodies to improve systematic and robust disaggregated data gathering and intersectional analysis about people who access and apply for SDS/ social care.

Information About SDS

3. People (service users and unpaid carers) need good access to publicly available, high quality information about SDS/ social care, in a range of accessible and tailored formats (e.g. hard copy and digital; face-to-face; large print; Braille; Easy Read; BSL). Information is required at different points in a person's journey through the social care system, e.g. finding out/ first enquiry about SDS, pre-needs assessment, during needs assessment, after needs assessment, once support is in place.

4. A wider pool of professionals (health, education) should be taught about SDS and how to signpost people to social work, independent support, and appropriate resources.

5. More information should be publicly available for people about what to expect from interactions with social work, and about their rights.

6. People should be provided with timelines for each stage of the process for accessing SDS, and transparency about where and when decisions about support are made. Transparency would be improved by sharing more publicly available information in accessible formats.

7. Sufficient time must be allocated for needs assessments and review meetings, to allow for detailed questions and consideration of the four SDS options.

8. Further information and training for professionals may be required about the SDS options and supported decision making.

9. Everyone should be informed about all four SDS options, rather than being given information about a more limited list of options, and supported to consider the advantages and disadvantages of each SDS option before making decisions.

10. Professionals should proactively check back in with people after assessments to ensure any outstanding concerns are addressed and resolved, and their care is working well.

11. People should be offered a variety of ways to contact social work, as best fits their access needs and preferences. Social work departments should consider different opportunities, including online chat functions, a freephone support line, and direct email addresses so that people can communicate effectively with social work professionals.

12. People should always have access to independent advocacy and support for assessments and review meetings if they desire.

13. People should be provided with paper or digital (as preferred) copies of all documentation pertaining to their SDS, including personal outcome plans, budget agreements, and decisions about their support package. These documents should be provided promptly and all materials should be available in a variety of accessible formats.

14. Everyone must have access to information about the budget available to them for their care and support.

15. People may want to take part in several conversations to support informed decision making about care charges, budgets and how they interact with other income like social security.

16. Any proposed changes (particularly increases) in care charges should be communicated clearly to—and discussed with—people who access SDS/ social care well in advance of the changes being introduced.

Informed Choice and Control

17. Systems could be improved to guarantee short waiting times – for a needs assessment, review, or for support to be put in place – to help people avoid unnecessary stress and anxiety, and deteriorations in their physical and mental health and wellbeing.

18. Targeted efforts are required to ensure that people living in rural areas of Scottish Borders have a meaningful choice between—and can access—all four SDS options and appropriate person centred, rights based care, without having to incur disproportionate expenditure or move house.

19. People must be treated with dignity and respect in all interactions with health and social care professionals.

20. Any proposed reductions in SDS budgets/support should be communicated clearly and discussed with people well in advance of any changes being introduced. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

21. People need flexible budgets and a focus on outcomes to enable them to live as independently as possible and enjoy the full range of their human rights. Flexibility is required in a range of ways: to change SDS option; to be able to choose how, where and when to spend personal budgets; with different amounts of spend and support at different times of the year.

22. Flexible, regular access to short breaks should be strongly encouraged because they are an essential element of SDS that result in good personal outcomes for people who access social care, families and unpaid carers.

23. People – particularly those living in more rural areas and those who are blind or partially sighted – require more acknowledgement and accommodation of travel costs in their SDS budgets.

24. Many people could benefit from assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.

25. Professionals should fully incorporate equality assessments into their processes for service users and families.

Communication and Relationships with Social Work

26. Existing good work should continue to ensure positive conversations and meaningful, consistent relationships, with ongoing planning to guarantee high quality practice for all people using SDS.

27. Social workers need to have the time and skills to build relationships and trust with the people accessing SDS and unpaid carers that they are working with.

28. People’s opinions (spoken or written) should be recorded

and acknowledged during needs assessments and review meetings to demonstrate the level of choice and control exercised over their support.

29. Social work professionals should be given training on how to support disabled LGBT+ people with targeted support and information if required, and local support groups should be appropriately funded.

30. Social work professionals should proactively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement.

31. Social work professionals should pro-actively inform service users, families and unpaid carers on a regular basis about how they can challenge decisions, access independent advocacy and support, local authority complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO).

32. Work is needed to ensure systematic good practice and consistent transparency across several elements of SDS/ social care, including eligibility criteria, needs assessments, budgets and support packages, changes to support, participation in decision making and how to challenge decisions.

33. Professionals should ensure that all unpaid carers are offered carer's assessments/Adult Carer Support Plans and have their rights explained to them.

34. Professionals should not assume that family members and friends are able or suitable to provide unpaid care. People who wish to reduce the amount of unpaid care they provide should be promptly supported by professionals, with appropriate future planning for contingencies.

35. Health and social work professionals should respect service users' preferences if they do not wish to be reliant on family members and friends for their care and support.

36. We encourage Scottish Border's Council to indicate document publication dates and webpage timestamps. The Council's website could also provide further information on their Equality Impact Assessments and the role these play in SDS/ social care decision making. To strengthen participatory decision making, Scottish Borders Council could set out the steps taken to involve people who use support, unpaid carers, and partner organisations in the development of eligibility criteria and the delivery of support. Further details of other engagement with people with lived experience would support greater transparency.

Care Staff, Recruitment, Training and Quality

37. Some people need more help to recruit and train care staff. Local authorities and health and social care partnerships should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality, including diversification of the workforce.

38. Care staff training costs (e.g. specialist first aid or medical training required for them to carry out their job appropriately) should be included in people's SDS budgets. This would

help ensure a quality care workforce (including PAs) in each local area.

Independent Advocacy and Support

39. Independent advocacy, independent advice and support services need sustainable resources to continue their important role in Scottish Borders.

40. Local authority and health and social care partnership staff should be given information and training about local independent advocacy, advice and support organisations, so they can refer people to these resources.

41. Social work professionals should proactively provide people with information about independent advocacy, advice and support organisations in accessible formats.

42. Local peer networks, including the Scottish Borders SDS Forum, should be encouraged and supported.

National and Local Context for SDS/ Social Care

National Context

Self-directed Support (SDS) is Scotland's approach to social care. It is defined as "the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed."[6] For more information about the national context of SDS/ social care in Scotland, please refer to the MSMC national report.[7]

Local Context

Scottish Borders is a council area with an approximate population of 115,000 people, across 54,000 households.[8] Scottish Borders is a largely rural area, covering a significant geographical area to the south of Scotland, and people live in both rural areas and towns. It is situated south of Edinburgh and Lothian, with Dumfries and Galloway to the west and Northumberland to the south.

Scottish Borders Council publishes a range of information for people who access or wish to access SDS on their website (searchable via the search bar on the council website).[9] This provides a definition of SDS, outlines eligibility criteria, introduces the assessment process and how people can manage support and budgets, and shares information on how direct payments are managed. Scottish Borders Health and Social Care Partnership also published a publicly accessible and relatively recent strategic social care plan (spanning 2019-2021),[10] and a comprehensive document, "Introduction to Social Care"[11] explaining the assessment process, eligibility criteria, risk categories, and further information about support services. They provide a similar document on "Preparing for Assessment".[12] These are all welcome examples of good practice in terms of transparency of process and clear information provision.

The website also signposts people to Encompass[13] (an independent organisation that supports people who use direct payments), and other resources and links to local independent support organisations – particularly for people who are not deemed eligible for SDS. Prior to COVID-19, the website also signposted the "What Matters Hub", a drop in community assistance forum that offered a range of sessions around social care.

The eligibility criteria outlined on the Scottish Borders Council website reflect the National Eligibility Framework, which categorises risk as being critical, substantial, moderate, or low:[14]

- Critical risk: indicates that there are major risks to an individual's independent living or health and well-being and likely to call for the immediate or imminent provision of social care services.
- Substantial risk: indicates that there are significant risks to an individual's independence or health and wellbeing and likely to call for the immediate or imminent provision of social care services.
- Moderate risk: indicates that there are some risks to an individual's independence or health and wellbeing. These may call for the provision of some social care services managed and prioritised on an on-going basis or they may simply be manageable over the foreseeable future without service provision, with appropriate arrangements for review.
- Low risk: indicates that there may be some quality of life issues, but low risks to an individual's independence or health and wellbeing with very limited, if any, requirement for the provision of social care services. There may be some need for alternative support or advice and appropriate arrangements for review over the foreseeable future or longer term.

The eligibility criteria outlined by Scottish Borders Council states that support is available to "those people who are at the greatest risk".[15] Support is not provided via SDS to people who are assessed as being at a "moderate" or "low" risk level, only those who are at "critical" or "substantial" risk. Scottish Borders Council defines these terms as follows:

- "Critical - major risks to your independent living or health and well being which are likely to require immediate or imminent provision of services.
- Substantial - significant risks to your independent living or health and well being which are likely to require immediate or imminent provision of services.
- Moderate - risks to your independent living or health and well being.*
- Low - issues around your quality of life but low risks to your independence and well being.*

* Resources are not available to meet these needs. However, we will provide you with information and advice about alternative sources of support with appropriate arrangements for review, if required."[16]

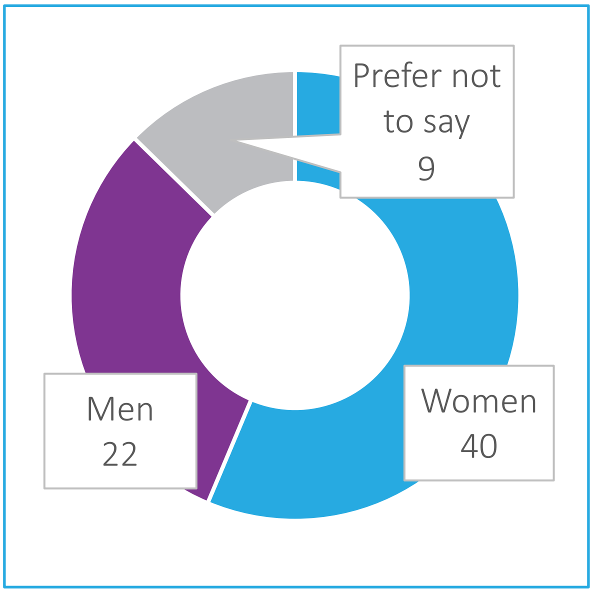
We encourage Scottish Border's Council to indicate document publication dates and webpage timestamps. The Council's website could also provide further information on their Equality Impact Assessments and the role these play in SDS/ social care decision making. Finally, to strengthen participatory decision making, Scottish Borders Council could set out the steps taken to involve people who use support, unpaid carers, and partner organisations in the development of eligibility criteria and the delivery of support. For example, we know from speaking to interviewees that Scottish Borders Council were in regular conversation with the Scottish Borders SDS Forum. Further details of other engagement with people with lived experience would support greater transparency.

Research Participants

MSMC heard about the experiences of 71 people who use or were being assessed for SDS in Scottish Borders. We interviewed 11 people who spoke about their own experiences and the experiences of other members of their household who use SDS (spanning the experience of a total of 13 people who use SDS or who were being assessed for SDS). A further 58 people from Scottish Borders completed the survey. Throughout this report some participant details (e.g. age) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. “My advocate, [Name], was great”).

Where possible, we have compared our participant data to local data and figures from Public Health Scotland’s (PHS, formerly Information Services Division) 2017-2018 experimental statistics on social care in Scotland.[17] While not comprehensive, PHS have demographic statistics on people using SDS, and accessing social care support services more generally, that is provided by local authorities, including Scottish Borders Council. PHS include people who use SDS within their wider discussions of people receiving “social care support”, but also include care home residents and people who use community alarms and telecare services (with or without SDS) in that wider definition.

Chart 1: Respondents’ gender



Gender

Overall, 40 women (56% of respondents) and 22 men (30% of respondents) participated in MSMC in Scottish Borders. A further nine people (13%) preferred not to disclose their gender.

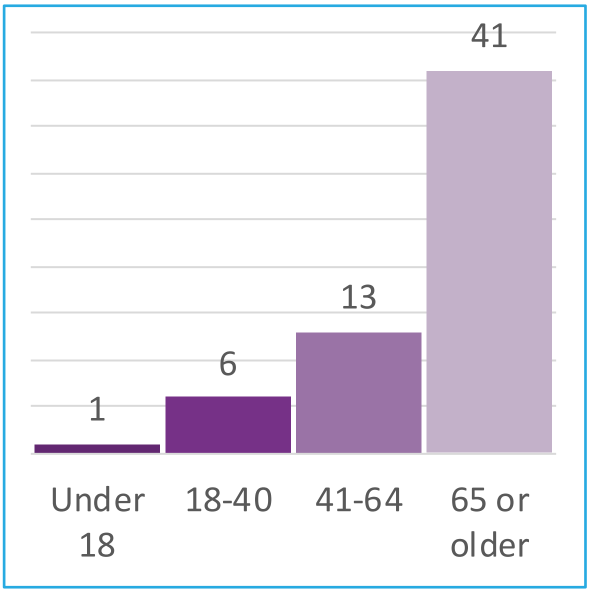
While PHS figures are not available for the division of men and women accessing SDS (nationally or in Scottish Borders), they do publish statistics on the number of men and women receiving social care support services more generally (of whom an estimated

39% access SDS). PHS reported that in 2017-2018 61% of people accessing social care support in Scottish Borders were women and 39% were men.[18]

Age

We asked all participants to share their age. Of the 61 people who chose to answer the question, one (2%) was under 18 years old, six (10%) were between 18 and 40 years old, 13 (21%) were between 41 and 64 years old, and 41 (67%) were 65 years or older.[19]

Chart 2: Respondents' age



In mid-2018, 55% of the population of Scottish Borders was over 45 years old (higher than the Scottish average of 47%), with the average age expected to increase, especially in the 75 and over age group.[20]

PHS do not provide an overall breakdown of age groups accessing SDS, although age group data is provided by SDS Option Chosen and Client Group Profile. PHS provide age disaggregated data on people receiving social care support services more generally within Scottish Borders (of whom an estimated 39% access SDS). PHS reported that in 2017-2018 in Scottish Borders, 77% of people accessing social care support were over 65 years old, 22% were aged 18-64, and 9% were under 18 years old.[21]

Ethnicity

50 MSMC survey respondents in Scottish Borders identified as white, and one survey respondent identified as "Asian, Asian Scottish, or Asian British". A further seven people chose not to describe their ethnicity. Most interviewees did not disclose their ethnicity when self-describing themselves, and the majority of those that did described themselves as "white".

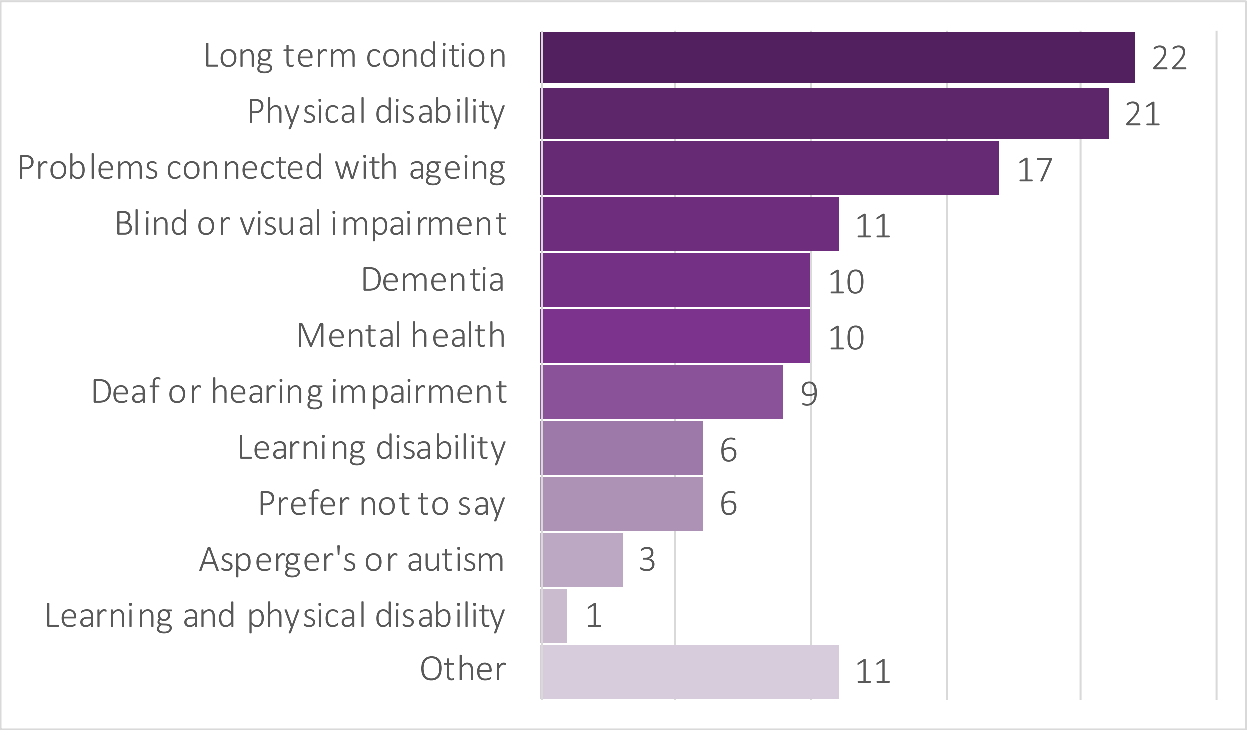
The 2011 Scottish Census indicated that 95.2% of the population of Scottish Borders identified as "White: Scottish" (78.8%) or "White: Other British" (16.4%), with a further 3.5% selecting "White: Irish" (0.7%), "White: Polish" (1.1%), or "White: Other" (1.7%). The remaining people identified as being part of minority ethnic groups: 0.6% of the population identified as "Asian", "Scottish Asian", or "British Asian", and 0.6% as belonging to "other ethnic groups". The overall spread of MSMC respondents is slightly less ethnically diverse than 2011 Scottish Census data for Scottish Borders.[22]

PHS do not provide a disaggregated breakdown of the ethnicity of people accessing SDS. They have some disaggregated data on the ethnicity of people receiving social care support services more generally (of whom an estimated 39% access SDS), using the limited categories of "White", "Other", and "Not provided/Not known". PHS reported that in 2017/2018 in Scottish Borders, 91% of people accessing social care support were "White", 8% were listed as ethnicity "not provided/not known", and 1% categorised as "Other" (including "Caribbean or Black, African, Asian and Other Ethnic Groups").[23]

Client Group/Disability/Long Term Condition

MSMC survey respondents in Scottish Borders self-identified as living with a range of conditions, with the majority reporting that they were living with multiple conditions. 22 people (30%) said they live with a long term condition, 21 people (30%) selected physical disability, and 17 people (24%) stated that they experienced "problems connected with ageing".[24]

Chart 3: Client Group/Disability/Long Term Condition (Survey)



Interviewees also discussed their conditions, and – if they were unpaid carers – those of the people for whom they care. Their reasons for accessing SDS were broadly in keeping with survey respondents'. Of the 13 people whose experiences of SDS we heard about during interviews, 12 accessed SDS because of their own conditions, and one was awaiting the result of their first assessment.

PHS listed the following client groups for people in Scottish Borders accessing SDS in 2017-2018: frail/elderly, physical and sensory disability, learning disability, dementia, mental health, other, and not recorded.[25] These broad categories do not directly align with those tracked in MSMC. As with MSMC, people could feature in more than one client group simultaneously. Overall, PHS estimate that 68% of people accessing SDS did so because they were "elderly/frail", 35% due to a physical or sensory disability, 12% because of a learning disability, 13% due to dementia, 9% as a result of their mental health, and 6% for "other" reasons. A further 0.4% did not have their reason for accessing SDS recorded.

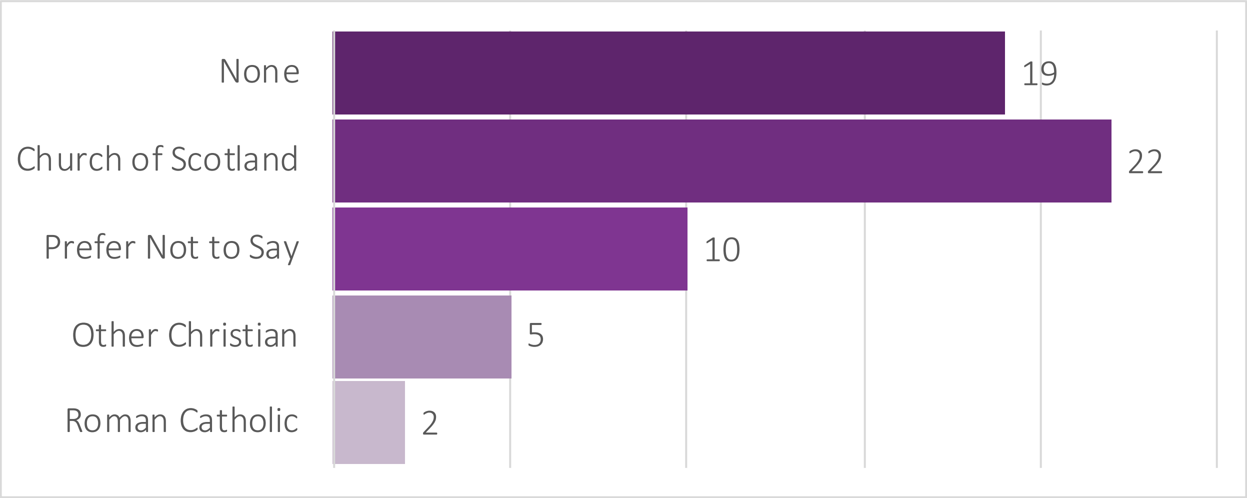
Religion

When asked about their religion (if any), 19 survey respondents (33%) stated "none", 22 were part of the Church of Scotland (38%), five described themselves as "other Christian" (9%), and two were

Roman Catholic (3%). Ten people (17%) preferred not to answer.

Most of the interviewees did not choose to explicitly disclose their religion when self-describing themselves. The overall spread of MSMC respondents is slightly less religiously diverse than 2011 Scottish Census data for Scottish Borders.[26] Data about people's religion is not available on the PHS dashboard.

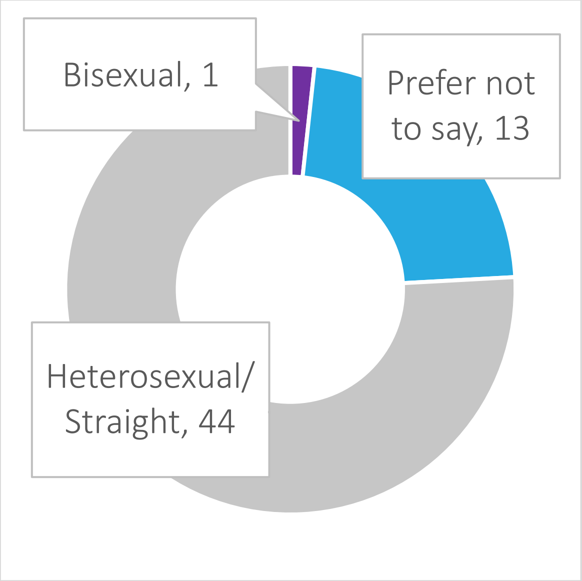
Chart 4: Survey respondents' religion



Sexual Orientation

44 survey respondents described their sexual orientation as heterosexual or straight and one person was bisexual. A further six people stated that they preferred not to disclose their sexual orientation, and seven people did not answer the question. The 2011 Scottish Census did not record data on sexual orientation at local authority level (although the 2022 Scottish Census is expected to do so); as such, we do not have local statistics on sexual orientation available as a comparison. Data on people's sexual orientation is not available on the PHS dashboard.

Chart 5: Survey respondents' sexual orientation



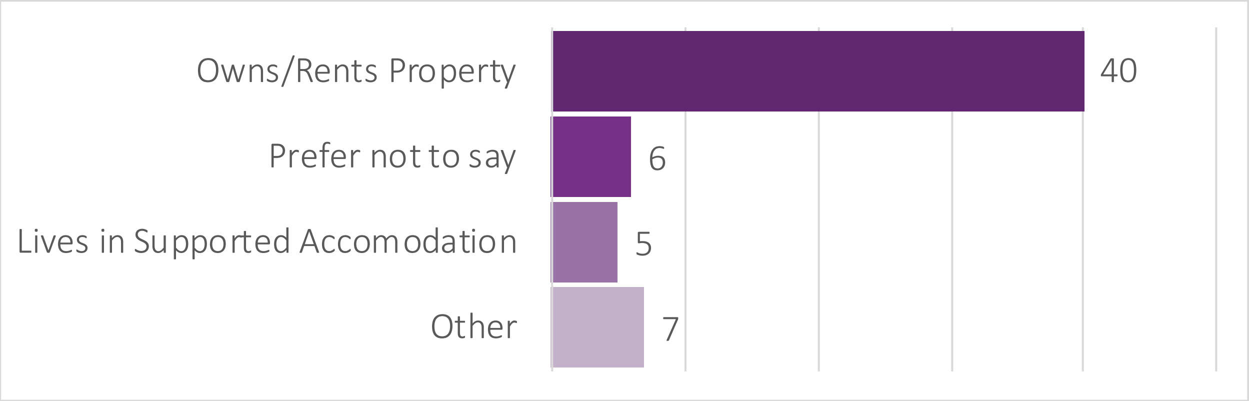
Housing

40 survey respondents (69%) either rented or owned their own home, six people (10%) reported that they lived in the home of a family member, five (10%) lived in supported accommodation, and one (2%) lived

in a "retirement flat for the elderly". Six people selected "prefer not to say" (10%). Data on people's housing situations (other than residential care) is not available on the PHS dashboard.

When discussing housing, several interviewees spoke about their current situations, spanning a similar range of options to survey respondents. Of those who discussed their housing arrangements, most people lived independently in their own home, followed by those who lived with a family member.

Chart 6: Survey respondents' housing arrangements

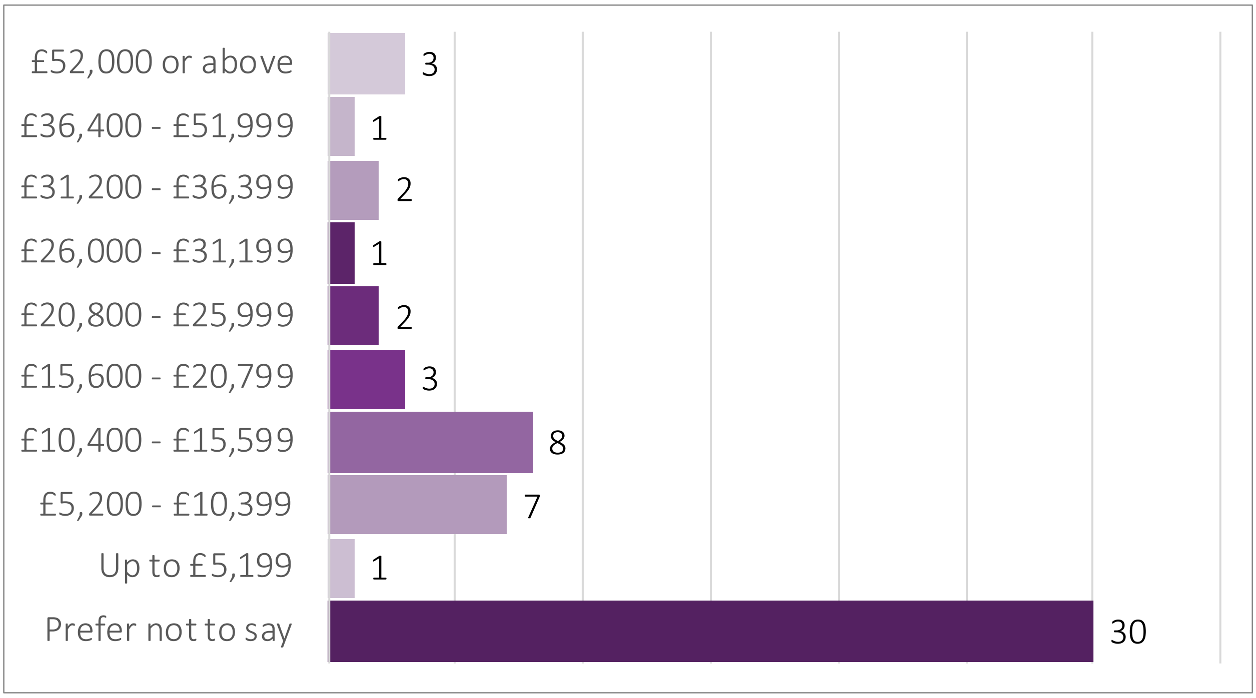


Household Income

We asked survey respondents about their household income. 28 survey respondents chose to disclose their annual household income. We were interested in this information because in Scotland an estimated 24% of households with a disabled person live in relative poverty after housing costs, compared to 17% of the population with nobody with a disability in the household.[27]

None of the interviewees disclosed their household income when self-describing themselves, although many commented on the negative impact that limited or reduced SDS/ social care budgets and social security entitlements had on their quality of life.

Chart 7: Survey respondents' annual household income



According to Scottish Government data, the median housing income in Scotland in 2015-2018, before housing costs, was £499 per week (£25,948 per annum).[28] The relative poverty threshold was defined as household income below 60% of the median, which for the same period was defined as £302 per week (£15,704 per annum).[29] Based on this definition, 16 (57%) of the respondents in Scottish Borders who chose to provide details of their household income are living below the poverty threshold. Data on the household incomes of people accessing SDS is not available on the PHS dashboard.

Poverty and SDS: Reductions in SDS budgets and tightened eligibility criteria can pose serious risks to people on low incomes who access or are trying to access social care. It can result in people having to manage without support, risks deterioration in physical and mental health, and unacceptable demands on family and friends to assume roles as unpaid carers.

SDS Option

Of the 46 participants in Scottish Borders who shared which SDS option they used, 19 people (41%) indicated they used Option 1, one person used Option 2, 13 people (28%) used Option 3, and seven people (15%) used Option 4. Six people (13%) stated that they did not know what option they used.

Figures from PHS indicate that in 2017-18 there were 448 people in Scottish Borders using SDS Option 1, ten using Option 2, 2,979 using Option 3, and 174 using Option 4.[30] In some instances, people are logged as being on two options simultaneously (e.g. Options 1 and 3) rather than Option 4, which distorts these figures.

Data Gathering and Analysis

As the chapter on research participants demonstrates, there are concerning gaps in SDS data gathering, analysis and reporting across Scotland. PHS have reflected on difficulties gathering disaggregated data on people's use of and experiences of SDS/ social care in their experimental statistics publication

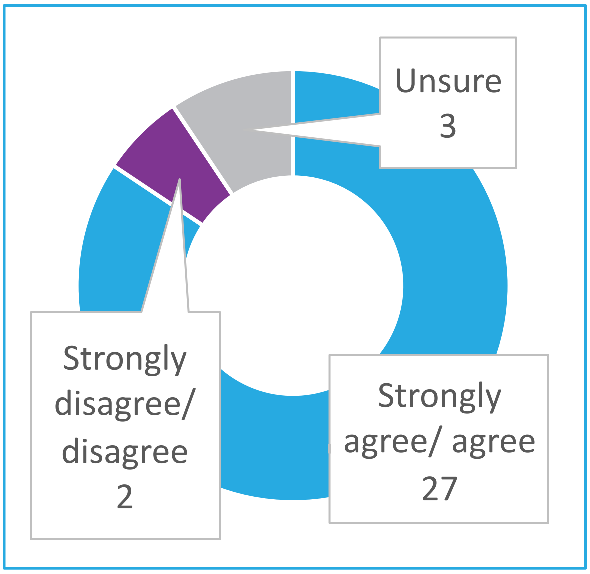
Insights into Social Care in Scotland.[31] They highlight differences in reporting periods for social care data across local authorities, and that some local authorities and social care partnerships were either not tracking or not able to share disaggregated data about SDS and the people using it.[32] Data gaps are also in part due to existing patterns of data collation – leading, for example, to the PHS Social Care Information Dashboard tracking ethnicity via the limited and problematic categories of "White", "Other", and "Not provided/ Not known".[33]

Data Gathering and Analysis: Disaggregated data gathering and intersectional analysis is essential to develop fully realised policies and practices that prioritise equal access to SDS/ social care for everyone, following human rights principles of equality, non-discrimination, participation and inclusion. To avoid gaps and improve analysis, we recommend systematic and robust data gathering by local and national public bodies on people who access SDS, disaggregated by all protected characteristics, including age, gender, sexual orientation, ethnicity, and religion, as well as socio-economic information like household income and the Scottish Index of Multiple Deprivation (SIMD).

Overall Experiences of SDS/ Social Care

We asked survey respondents whether they felt that SDS had improved their social care experience. Of the 32 people who answered this question in Scottish Borders, 27 (84%) stated that they "strongly agree" or "agree" with the statement "SDS would/has improve/d my social care experience". Two people (6%) strongly disagreed and three (10%) were unsure. This was a higher satisfaction rate than across Scotland more broadly (74%).

Chart 8: "SDS has improved my social care experience" (Survey)



Survey respondents and interviewees were asked to share an overall summary of their experiences and any advice they might have to offer other people considering using SDS. Several of the participants' statements were positive, such as:

> *"I have been delighted with the removal of stress."*

> *"It allows you to be flexible and in control of your own support."*

> *"I would say do this. It's fantastic and means I choose who works for me and what time they come; it totally meets my needs."*

> *"It is good, I am pleased I have done it, but it was very hard."*

> *"SDS kept my independence, […] giving me that kind of control and flexibility that ensures that I live my life the way I want to live it, rather than being dictated by agencies or other people's ideas of how I live my life. That, for me, is the biggest part of it."*

However, some people were more cautious or explicitly negative about SDS, particularly relating to difficulties with paperwork and assessment processes, and insufficient budgets:

> *"I would recommend it as it gives you as much self advocacy as possible in your care options, but also be aware that it is not a blank slate, there are still restrictions. But it was the best option by miles for our circumstances."*

> *"Read up on SDS. Be prepared for a fight with social work. Be prepared to be fobbed off and told there is no money. Be prepared to be only given one option. Stand up for yourself and your family. Be really clear what it is you want from SDS."*

> *"If what we experienced was SDS I would suggest that [other people] don't waste their time."*

> *"Stay clear […] not very professional or competent and will get nowhere, probably a money saving tactic."*

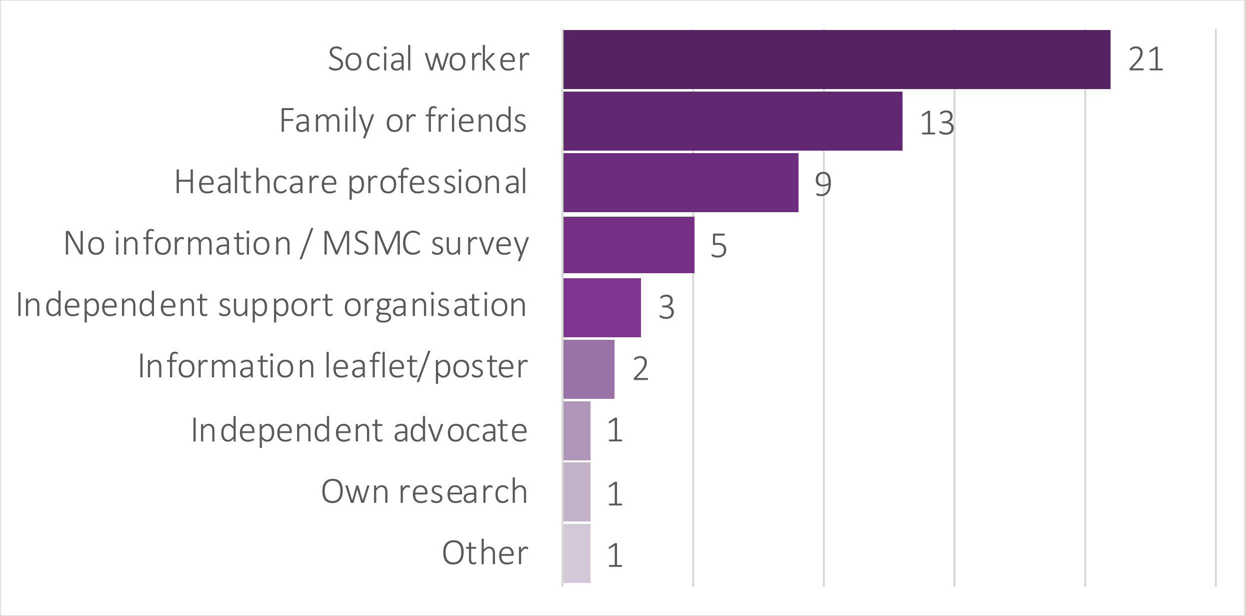
Information About SDS

Finding Out About SDS

We asked participants in Scottish Borders how they first found out about SDS.

21 survey respondents (38%) first heard from a social work professional (e.g. a social worker/social work assistant or an occupational therapist), 13 (23%) heard from friends or family members, and nine (16%) from NHS health staff, including nurses working in the community. A further three people (5%) first head about SDS from an independent support organisation, two from an information leaflet/poster, one from an independent advocate, one from their own research, and one from an unspecified "other" source.

Chart 9: How did survey respondents first hear about SDS?



Five survey respondents reported that they had never received information about SDS, of whom three stated that they first heard about SDS via this research project. Some interviewees also said that they did not understand or had not had SDS fully explained to them, even though they used SDS, and had done for some time.

Among the interviewees, social work was the most common method through which people first heard about SDS – usually mentioned alongside Encompass, as twin sources of information. This was followed by people hearing from friends or family members, information leaflets, and one person's GP.

The interviewees who first heard about SDS through their social workers praised the assistance they provided. One interviewee highlighted their social worker's role in helping them to realise that they needed more support and telling them about SDS. They explained that:

> *"It was my social worker. […] I was having bother keeping my house in order and [they] actually came around one day and was alarmed by the state I had allowed to get it into. 'You need help to get this sorted out', [they] said. […] So that was how Self-directed Support came in."*

Other interviewees indicated that friends provided them with information and advice about SDS. One participant changed their SDS option after they discussed their support with a friend, having previously been unaware of the different options:

> *"I actually heard about [Option 1] from a friend. I was using the council service at that time, but […] I was getting totally frustrated with it, because I worked more hours then, I was working more towards full time at that point. […] They had their times, they had their slots, and you were to fit into that. […] So, I was talking to a friend who was on direct payments […] so I shifted over, and it was the best thing I ever did, to become the employer."*

A different interviewee reported that they were advised to access SDS by their GP, and to do so promptly:

> *"The local doctor said, 'You better apply for care because it's going to be more difficult, they are going to close the doors in a little bit. You better apply now.'"*

One interviewee recounted that realising that they needed support was not easy and involved some self-denial. An advocate (employed for another purpose) then suggested that they would benefit from accessing SDS, which proved helpful. Another interviewee described how a family member read about SDS at a public information event in another local authority. This led to the family requesting a needs assessment from their local social work department, and a SDS package was instated.

Finding Out About SDS: The research indicates that people in Scottish Borders generally had good experiences finding out about SDS from social work professionals and local independent support and advice organisations (specifically Encompass, in several cases). There are some people in Scottish Borders who require improved access to information about SDS, and it would be helpful to widen the pool of professionals who are informed about SDS and can encourage people to access it. Making more use of educational professionals, hospital staff, GPs and other community health practitioners would be valuable in increasing the range of sources of information for people, as well as building on the existing expertise and resourcing of social workers and independent advice and support organisations.

Information and Preparedness Before Assessments

We asked survey respondents how much information they received on each of the SDS options before meeting with a professional to discuss their support, and whether it was enough information for their requirements.

As the chart indicates, across the SDS options most respondents in Scottish Borders received "all the information [they] wanted" (respectively, 60% (Option 1), 41% (Option 2), 50% (Option 3) and 63% (Option 4)). However, it is concerning that most people for Option 2, and a large minority of people across the other three options, either had no information or were left wanting more in advance of their assessment. The detail of those who wanted more information is as follows:

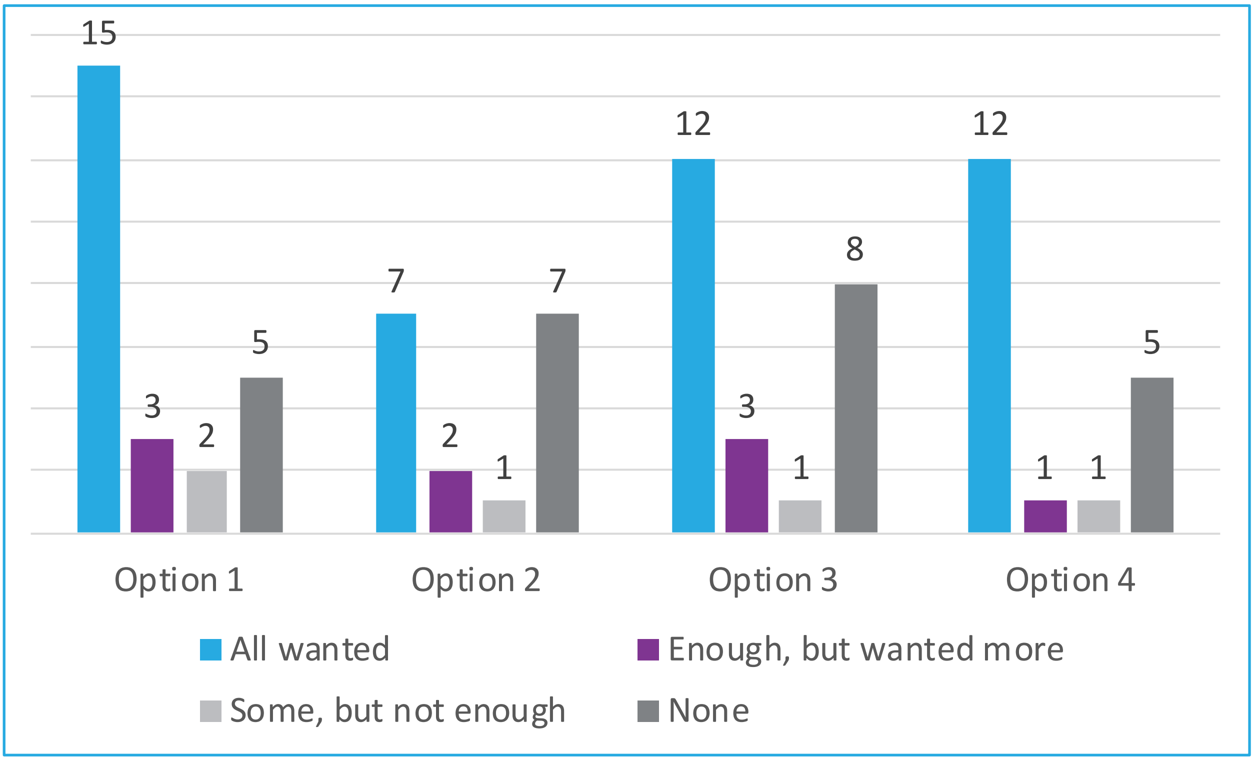
Option 1: 28% of respondents said that they received "some, but not enough" or no information, and 12% received "enough but wanted more".

Option 2: 47% of respondents reported that they had "some, but not enough" or no information, and 12% received "enough but wanted more".

Option 3: 38% of respondents said that they had "some, but not enough" or no information, and 13% received "enough but wanted more".

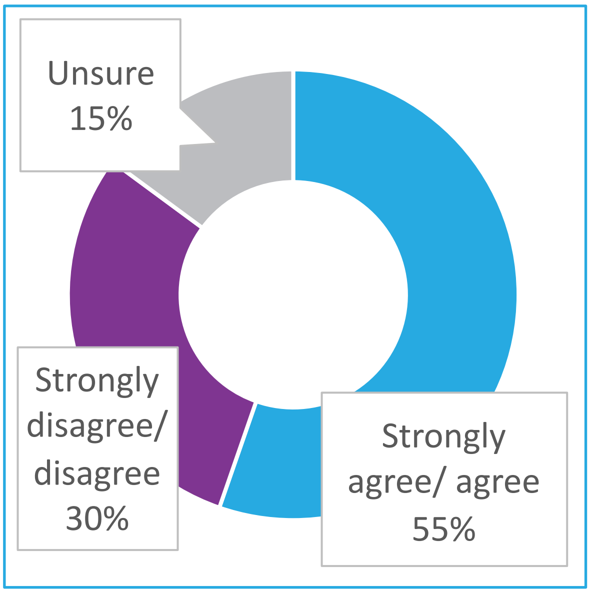
Option 4: 32% of respondents said they had received "some, but not enough" or no information, and 5% received "enough but wanted more".

Chart 10: Information received before discussing support (Survey)



We also asked survey respondents whether they felt prepared for their needs assessment. Of the 47 participants who answered the question, 26 (55%) strongly agreed or agreed, 14 (30%) disagreed or strongly disagreed, and seven (15%) were unsure. While it is encouraging that just over half of respondents in Scottish Borders felt prepared for their assessment, it is concerning that nearly a third felt unprepared and the rest were unsure.

Chart 11: "I felt prepared for my needs assessment" (Survey)



Some interviewees in Scottish Borders had been fully informed about the options prior to their assessments, but others had not been told about all four options when they started the process of accessing SDS. Those that felt well prepared for their initial assessment usually credited an independent support and advice organisation for providing them with appropriate information (including Encompass).

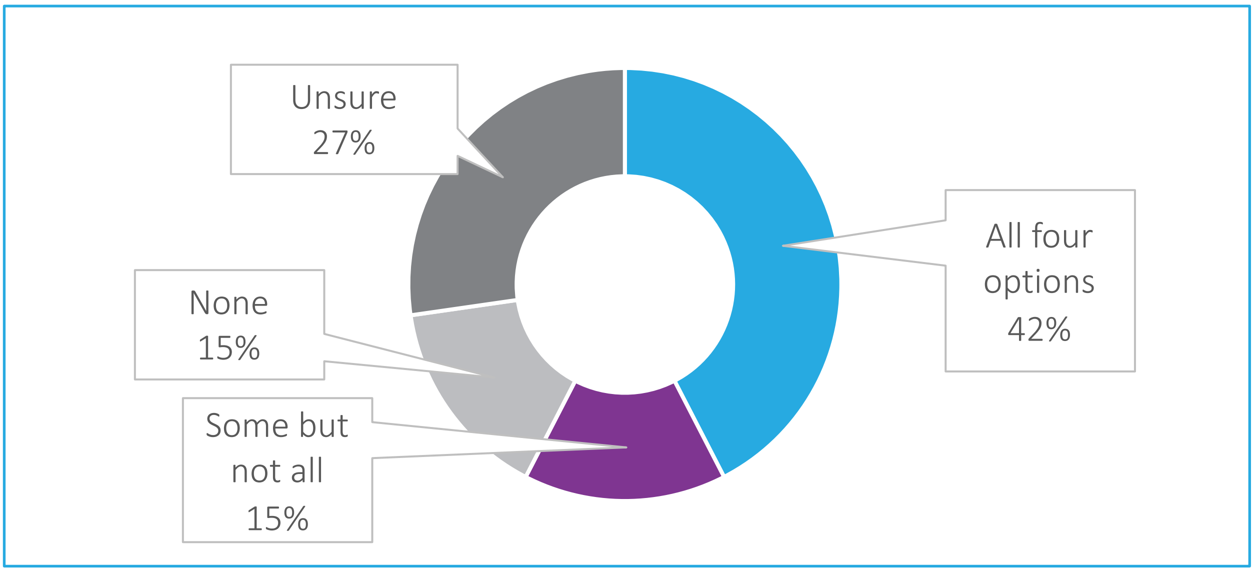
Information and Preparedness Before Assessments: The findings indicate that improvements could be made to ensure everyone in Scottish Borders has adequate information in advance and feels prepared for a needs assessment. Comprehensive, high-quality information in a wide range of accessible formats should be proactively provided to people about the four SDS options – particularly Options 2 and 3 – carers' assessments and support plans, and what to expect of a needs assessment.

Information During Assessments

The pattern of variable information about the four SDS options continued into people's needs assessments. We asked respondents whether all four SDS options were discussed with them when they met with a professional to discuss their support needs.

Of the 52 survey respondents, 22 (42%) stated that the professional discussed "all four options" with them, eight (15%) that "some but not all" options were discussed, and eight (15%) that "none" of the options were discussed. A further 14 respondents (27%) indicated that they were "unsure" which options were discussed with them. These findings indicate that more work is needed in Scottish Borders to ensure that all four SDS options are outlined and discussed with people during needs assessments and reviews.

Chart 12: Discussing SDS options with professionals (Survey)



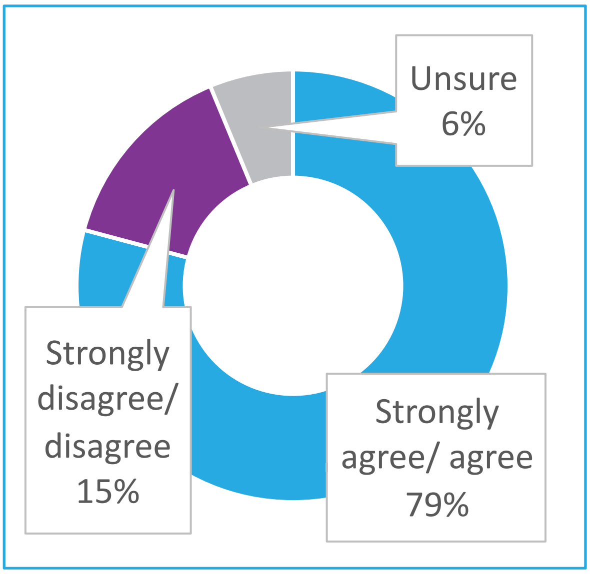
Three interviewees reported that they had not had all four options discussed with them during their needs assessment. Nevertheless, two of these interviewees were happy with the option of SDS they received, as the following comments show:

> *"It worked out extremely well. I think the social worker had our interest at heart and [they] thought it would be best. And it was. It was the best option."*

> *"I wasn't aware of the fact that there were going to be four options, but the reality is, the option that I settled for, is the best option for me."*

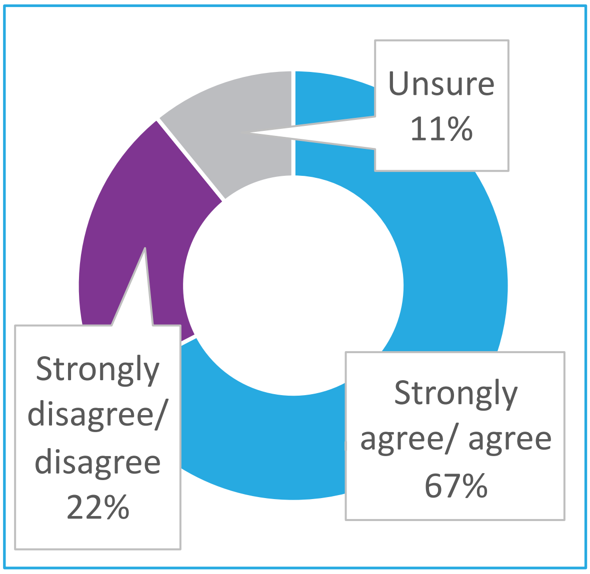
In the survey, we asked whether people agreed with the statement "The person I met with explained things clearly to me". 38 respondents (79%) strongly agreed or agreed, seven (15%) disagreed or strongly disagreed, and three (6%) were unsure. It is encouraging that such a high proportion of survey respondents report clear explanations.

Chart 13: "The person I met explained things clearly to me" (Survey)



In the survey, we also asked people to respond to the statement "All my questions were answered", regarding their meeting with a professional. Of the 46 respondents, 31 (67%) strongly agreed or agreed, ten (22%) strongly disagreed or disagreed and five (11%) said that they did not know. Interviewees indicated similar experiences. While a high proportion of respondents in Scottish Borders indicate that all their questions were answered, the finding that around one third disagreed or did not know indicates work may be needed in this area.

Chart 14: "All my questions were answered" (Survey)



Several interviewees reflected on positive experiences during their needs assessments and reviews. One interviewee described their experience as "excellent", saying that their social worker was "very careful to make sure they had the right impression", including writing "a draft that went backwards and forwards a couple of times between us of the needs" before a final draft was agreed. Two participants said that they have reviews every six months. In both cases, they felt this was a positive approach since their social worker was able to monitor their situations more closely and adjust support hours if necessary, producing a more flexible pattern of support based on the latest information around their needs.

However, other interviewees recounted more mixed experiences. Some people reported that the conversations they had with professionals felt rushed, or that social workers did not explain the process around SDS properly to them in a way they could understand. One interviewee mentioned that care provider contracts caused them some confusion, as they had not been made aware during conversations with social work that contracts would be required. They reported that:

> *"They didn't touch on having to sign a contract until weeks later. I wasn't aware of that at the time, which seemed a bit odd. Either I've missed it, or… But I certainly wasn't aware. I wasn't made aware to the point where I could say: 'well, this is not what I want to do'."*

A different interviewee requested assistance with paperwork, as they could not read the small print. They did not feel like the social work professional who visited to read the contracts to them relayed everything, instead skimming over sections. They summarised their concerns as follows:

> *"Every time there was a section that sounded to me a bit awkward, the reply was, 'Oh, don't worry about this, we'll take care of that'. But […] if something goes wrong, I, as an employer, would be liable. And I have got some legal experience, and I just didn't like the sound of it. Normally, things go fine, but when they don't, it could be quite serious."*

It is welcome that a social work professional came out to read the paperwork to the SDS user mentioned above. However, it is important that people have access to all the relevant sections of paperwork and contracts surrounding their SDS, in order to be fully informed about and in charge of their decisions.

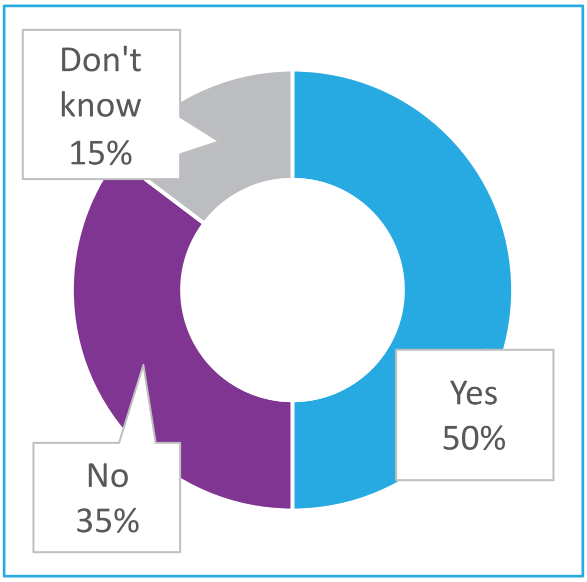
Overall, interviewees indicated that their questions to social work professionals covered a range of concerns, including how support package decision making processes worked, expected wait times, and the impact of SDS on other entitlements, including social security.

Information During Assessments: Social work professionals play a significant role in informing and influencing decisions about social care, and they are often many people's first port of call for information about SDS, including eligibility criteria, wait times and available support. The research indicates that there are positive examples of good practice in Scottish Borders. However, further work is needed to ensure that everyone is fully informed about all four SDS options during assessments, all questions are answered, and that social work professionals consistently practice supported rather than substitute decision making. Information in a range of accessible formats, access to independent advocacy and support should be easily available to all. For some people, information is best provided face-to-face, and more than one conversation may be needed. Enough time should be allocated to ensure meetings are not rushed.

Information About Budgets

We asked survey respondents if they had been told the amount of money they can spend on their support (sometimes called an estimated or a personal budget). Of the 34 respondents, 17 (50%) said yes, 12 (35%) said no, and five (15%) said they did not know if they had been given a budget.

Chart 15: “Have you been told the amount of money you can spend on your support?” (Survey)



That 50% of respondents in Scottish Borders had received information about how much money was available to them is a positive finding. However, it is concerning that a substantial minority – over a third of respondents – either had not received that information or were unsure. It is vital for informed decision making that people are given full information about their personal budgets.

In addition to these concerns, several participants reported that they did not receive enough information about their budget, particularly potential impacts on social security entitlements and when they should expect the first payments to process. For example, one interviewee with a personal budget felt that there was not enough information and guidance on how Universal Credit would affect their chargeable contributions towards SDS. They highlighted that they were uncertain as to how the introduction of Universal Credit would affect other entitlements (e.g. the Motability Scheme), and did not feel their social worker was well equipped to respond to their queries on this matter.

Information About Budgets: In order to support and enable people to make informed decisions about their care, measures should be in place to ensure that everyone is provided with accessible information about the budget available to them, how it may interact with other income, and payment procedures (including wait times). Some people may want to take part in several conversations with well-informed professionals to support informed decision making about care charges, budgets and how they interact with other income like social security.

Outstanding Concerns and Appeals

In the survey we asked if people had any outstanding concerns that were not addressed during their last assessment. Of the 51 respondents, 26 (51%) had no concerns, ten (20%) had outstanding issues, and 15 (29%) were unsure.

Of those respondents with outstanding concerns, the main issues were budgets, delays in implementing care, difficulty accessing public transport – especially in more rural areas of Scottish Borders – and a lack of information about SDS. Respondents highlighted that these issues had direct and negative impacts upon their health and the health of the people for whom they care.

Some interviewees also highlighted outstanding concerns about their support, specifically around transparency of process, accessible information, budgets, difficulties with travel in rural areas (and the importance of acknowledging that in SDS budgets) and waiting times. Some people highlighted that living in a rural area of Scottish Borders effectively meant that they could not access all four options of SDS, due to limited care options. They also commented that rural living increased travel costs for themselves and (in some cases) their PAs.

We also asked survey participants whether they were in the process of appealing the decision made in their last review or needs assessment. Of the 39 respondents, two people in Scottish Borders indicated that they are in the process of appealing the outcome of their last social care assessment or review. One person reported that they were being supported in their appeal by an independent support organisation.

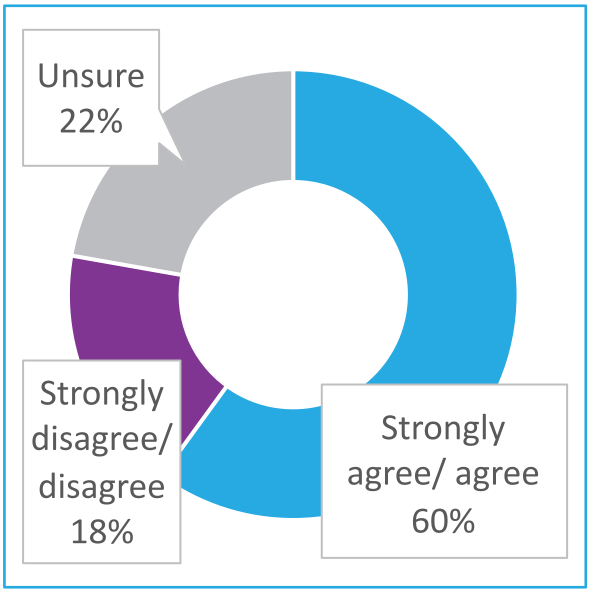
Outstanding Concerns and Appeals: The research invites further work in Scottish Borders to strengthen and embed existing good practice to ensure that people are not left with unaddressed concerns following needs assessments. People should be provided with alternative, accessible communication routes – like online chat functions, a freephone support line, and direct email addresses for professionals – that allow them to follow up and have questions answered later, if it is not possible during meetings. Social work professionals should proactively check in with people after assessments to identify and address any outstanding concerns. They should also signpost and refer people to other sources of information, including independent advice organisations (e.g. for assistance with Universal Credit).

Informed Choice and Control

Time to Consider Options

In the survey, we asked if people agreed with the statement “I had enough time to choose the option of SDS that suited my needs.” Of the 45 respondents, 27 (60%) agreed or strongly agreed, eight (18%) disagreed or strongly disagreed, and ten (22%) stated that they did not know. While it is encouraging that most respondents in Scottish Borders had enough time to choose an SDS option, the findings suggest that improvement work may be required to improve the number of people who feel they have enough time to decide on the best SDS option for them.

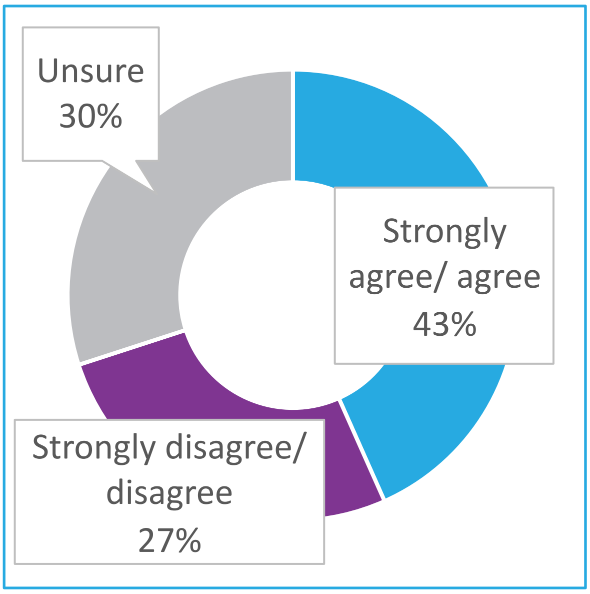
Chart 16: Enough time to choose SDS option (Survey)



Waiting Times

In the survey, we asked people to agree or disagree with the statement, "Waiting times, or waiting for responses, makes Self-directed Support more difficult for me." Of the 30 respondents, 13 (43%) strongly agreed or agreed, eight (27%) disagreed or strongly disagreed, and nine (30%) stated that they were unsure.

Chart 17: "Waiting times, or waiting for responses, makes SDS more difficult for me" (Survey)



Interviewees reported variable wait times for assessments and support to be put in place; some waited three or four months, while others waited a year before the start of support provision. One person waited three years before receiving support.

Interviewees uniformly appreciated short waiting times for a response or decision from social work. Those who waited the longest generally reported the highest levels of stress and difficulty in accessing SDS. One interviewee summarised their experience as follows:

> *"We waited so long to get a social worker [dates provided; three years]. So, all that time I had nobody at all. [...] And the GP didn't suggest it, the psychiatrist didn't suggest it, nobody did. I didn't know I could refer myself, but my [adult child] googled, you know, what help is there for people. [...] I think the social worker student came around about [date], and nearly a whole year went by before a social worker actually turned up, by which time I thought the whole thing was complete rubbish."*

It is worth acknowledging that the interviewee described the social worker that eventually assessed them as very helpful, "just a breath of fresh air, just so good." However, the interviewee highlighted that the long wait to obtain support affected their health and caused considerable stress.

Other respondents commented on additional waiting times that they did not expect, between initial phone contact with social work, assessments, decisions on packages and finances, and finally the eventual implementation of support. People indicated that more information about waiting times would have been useful in helping them manage expectations and plan accordingly.

Waiting Times: Short waiting times are greatly appreciated because when people have to wait too long – whether for a needs assessment, review, or for support to be put in place – it causes unnecessary stress and anxiety. Delays, compounded by barriers to accessible information and alternative support, must be avoided as they can lead to a deterioration in people's physical and mental health and wellbeing. Timely support can help people avoid reaching crisis point and the potential for more invasive and expensive intervention later. More publicly available information about waiting times would help increase people's understanding of what to expect of the process.

Choice over SDS Option and Support

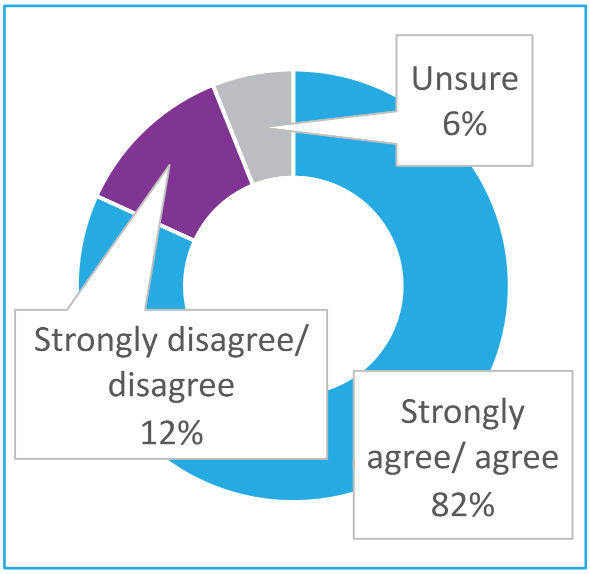
We asked survey respondents if they were on their preferred SDS option. Of the 33 participants who answered, 30 (91%) were on their preferred option and three were unsure (9%). This is a higher satisfaction rate than across Scotland more broadly.[34]

A similar pattern was found with interviewees. 11 out of 13 people whose experiences of SDS we heard about via interviews were on their preferred SDS option. One interviewee was unsure which SDS option they used, and another had recently decided to change their SDS option.

The proportion of respondents in Scottish Borders indicating they are on their preferred SDS option is highly encouraging. These people described how support arrangements enable them to do a diverse range of activities. These included (but are not restricted to): personal care, assistance with household tasks and shopping, short breaks, access to educational facilities, and support with social activities.

We also asked survey respondents to agree or disagree with the statement "I am fully involved in all decisions about my care and support". Of the 33 respondents, 27 (82%) strongly agreed or agreed, four (12%) disagreed or strongly disagreed, and two (6%) stated that they did not know. These findings are also highly encouraging, and higher than the national average in MSMC – where 74% of people agreed that they are fully involved in decisions, 18% disagreed, and 8% were unsure.

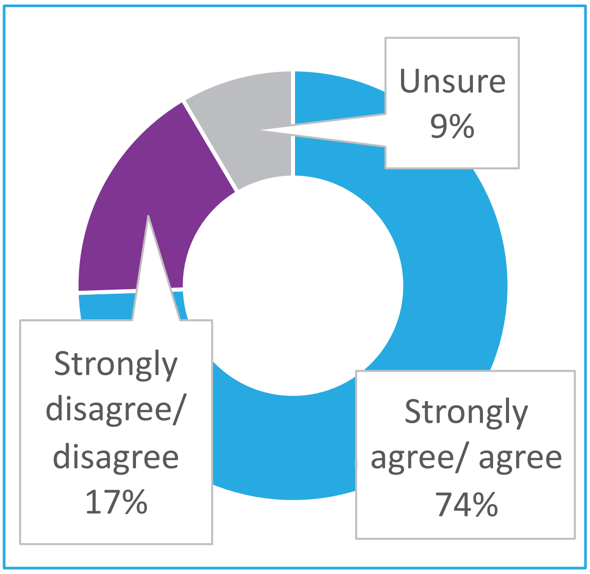
Chart 18: "I am fully involved in all decisions about my care and support" (Survey)



We also spoke to interviewees about which SDS option they had chosen. One interviewee detailed how they decided to change their SDS option as they felt unhappy with the initial decision. They recounted that a support provider and their social worker persuaded them to choose SDS Option 1 during the initial assessment process. However, the interviewee felt uncomfortable with the role of employer and opted to change to Option 2 (which their social worker facilitated). Once this was settled, they were satisfied with how their needs were assessed and the support they received. They said that although the social worker had originally encouraged them to choose Option 1, their social worker "was quite happy to agree to some changes. I thought [they] made a very fair assessment." While the interviewee had originally felt pressured into choosing Option 1, they presented the flexibility to change to another option – and the support to do so that was provided by their social worker – as an example of good practice.

In the survey, we also asked people to respond to the statement "I had a say in how my help, care or support was arranged." Of the 47 respondents, 35 (74%) strongly agreed or agreed, eight (17%) disagreed or strongly disagreed, and four (9%) stated that they did not know.

Chart 19: "I had a say in how my help, care or support was arranged" (Survey)

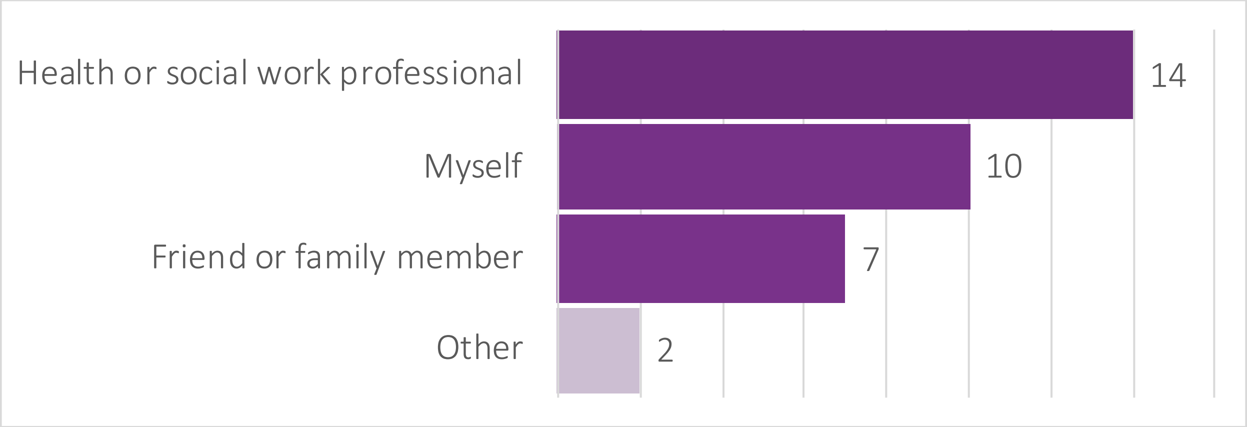


We also asked survey respondents who chose the way that their support is arranged now. Of the 33 respondents, ten (30%) said that they chose the way their support was arranged, six (18%) said that a social worker chose their support for them, four (12%) stated that an occupational therapist chose for them, three (9%) that their care manager chose, and one person said that a nurse chose their support.

Combined, that is a total of 14 respondents (42%) who reported that health and social care professionals chose how their support is arranged. These findings invite further work to embed supported decision making (instead of substitute decision making) in SDS/ social work practice.

A further seven people (21%) stated that a friend or family member chose for them, one person selected "other" and stated that "everyone" took part in the decision, and another person stated that the decision was shared between them and their social worker.

Chart 20: Who chose support arrangements? (Survey)



We also heard from interviewees about their SDS option choice. Some people felt that their social worker had decided what SDS option they would choose before completing the needs assessment (this finding corresponded with reports that they did not have all four options explained to them).

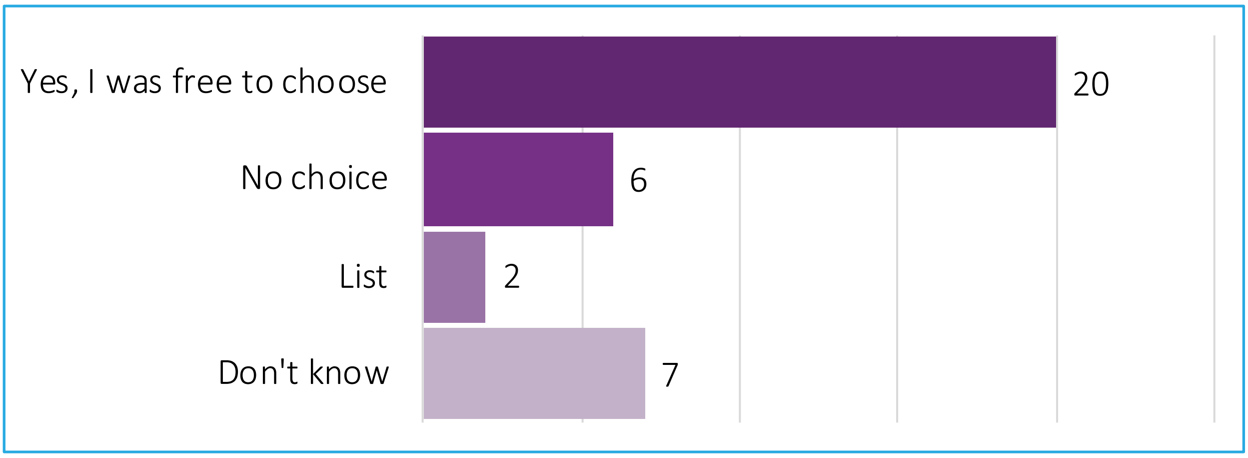
Other interviewees highlighted the importance of access to information to make informed decisions, since they felt that they were at the mercy of what knowledge their social worker had, especially around Option 1.

Choice Over SDS Options and Support: Although the majority of respondents in Scottish Borders indicated they were on their preferred SDS option, improvements could be made to information-sharing and decision making processes to ensure consistent practice is applied to SDS option choice. While professionals play an important role in helping people access appropriate services, that should not extend to making decisions on people's behalf – the principles of choice and control are clearly embedded in SDS legislation and policy. Staff could be given more training about how to support decision making rather than lead it, and on co-production methods more broadly. Professionals should also fully incorporate equality assessments into their processes for service users and families.

Budget Management

We asked survey respondents whether they chose who manages their personal budget, and if so, who they chose to manage it. Of the 35 respondents, 20 (57%) said that they were free to choose who they wanted to manage their personal budget, two (6%) chose from a set list of providers given to them by a social work professional, six (17%) said they were not given a choice, and seven (20%) were unsure whether they had a choice.

Chart 21: Did you choose who manages your personal budget? (Survey)



Of the 20 people who were given free choice of who would manage their personal budget, six (30%) selected the local authority, four (20%) chose a third sector provider organisation, and two (10%) selected an independent support organisation. A further six people (30% of those who were free to choose) selected an individual person (this response could include themselves). Two people were unsure who they had chosen to manage their budget.

Of the six people who said that they were not given a choice, and the seven who were unsure whether they had been offered a choice, none provided details of who manages their budget.

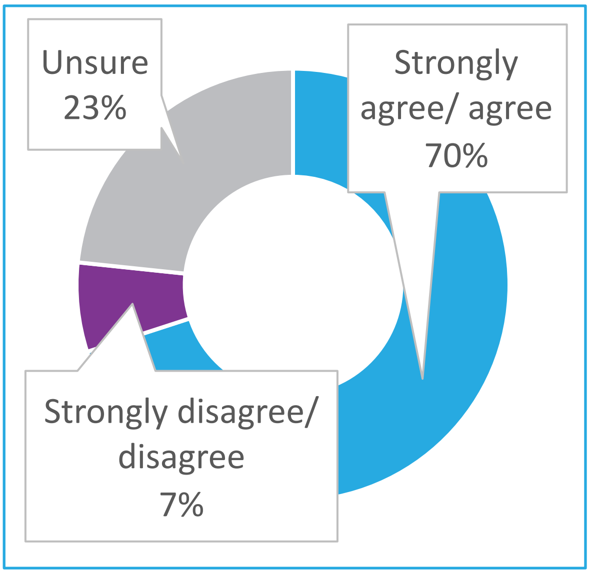
It is encouraging that most respondents in Scottish Borders were offered the choice of who to manage their personal budget. However, it is concerning that a fifth of respondents were unsure if they had a choice, and a similar number reported they had no choice. This indicates that, amongst other things, these respondents were not fully offered all four SDS options (as that would necessitate discussion of who would manage their personal budget).

Budget Management: The findings indicate that further work is needed in Scottish Borders to ensure everyone is offered a meaningful choice of all four SDS options and the opportunity to choose who will manage their personal budget.

Adequate Support

We asked survey participants to respond to the statement “Enough budget to meet my outcomes makes Self-directed Support easier for me”. Of the 30 respondents, 21 (70%) strongly agreed or agreed, two (7%) disagreed or strongly disagreed, and seven (23%) were unsure.

Chart 22: “Enough budget to meet my outcomes makes SDS easier for me” (Survey)



Some interviewees spoke in detail about the impact on their physical and mental health of substantial reductions to their SDS budgets and support. Two separate interviewees recounted how during recent reviews their SDS packages were reduced to just covering some personal care – even though their needs had not changed. They felt that social work expected unpaid carers to cover more personal care than previously, and that the importance of support to engage in social activities was not acknowledged (despite this featuring within personal outcome plans). One interviewee, an unpaid carer, and their partner summarised their experience of reduction in support for social engagement as follows:

> *“But [now SDS] is purely for personal care. […] So that’s what it is now. At the beginning as I said, [Name] used to go out to the garden, that was [name's] intertest, nothing else. And then going out for lunch, we could go twice a week, couldn’t we? We went to the golf course and places. And that came out, that was his social getting taken out, see what I mean? But not now. They took that away.”*

As a result of the reduction in support, the interviewee and their unpaid carer stated that their lives have been restricted and their quality of life reduced.

Other people commented on the sense of precarity from regular reassessments, and the fear of losing key elements of their budget and their ability to live independently. One interviewee summarised their perspective as follows:

> *“In the background […] is the precariousness of all the funding. […] So […] I’ve got this ‘Oh, they’re going to re-assess everybody’, and you know, sitting and waiting to see when and if that re-assessment*

> *is going to happen, and how that's going to impact on the whole package that I've developed, which works very effectively for me. Changing one bit of it would be like a house of cards, and everything would come falling down. […] And I suppose another challenge is if anything changes, it takes a fair bit of time to get somebody out. I have no dedicated social worker and there is no appointed social worker in the council."*

Two interviewees also reported that inadequate budgets led to SDS users using personal contributions to supplement care workers' pay, particularly when they had encountered difficulties recruiting or retaining personal assistants (PAs) (which was more common amongst MSMC respondents in rural areas across Scotland). They highlighted that the amount granted towards wages for PAs or agencies tended to underpay staff or compel a choice of the cheapest care provider. Interviewees argued that instead of costing labour at the lowest common denominator, the best value for money should be viewed in terms of quality of life for service users and care staff. Several respondents in Scottish Borders also highlighted issues with limited support options in their local area, leaving them without meaningful choice of providers.

As well as reporting on the negative impacts of cuts to social care support, several respondents described care arrangements that were not suitable – mostly centred around inflexible timings of personal and home care. Given the concerns raised about effective communication of SDS options, it is reasonable to assume that some of these issues with individual care providers could be mitigated if – for example – individuals knew they had the freedom to move from Option 3 to Options 2 or 1 and receive support from different care providers or PAs.

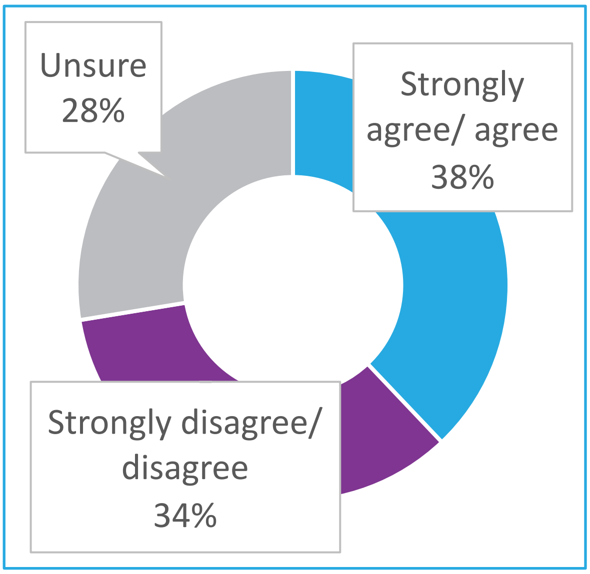
Adequate Support: The research reinforces the need in Scottish Borders for good quality, adequate support via SDS that acknowledges the importance of community engagement and social activities. This can be instrumental in ensuring good quality of life and plays an important role in helping people enjoy their right to independent living and equal participation in society. Unfortunately, we found that some people were not receiving adequate, person centred support in Scottish Borders. The impact of not providing rights based, person centred care can be devastating, resulting in isolation, loneliness and physical and mental ill-health. It can also place unacceptable demands on some people to act as unpaid carers without any choice by themselves or the people they care for. Any proposed reductions in SDS budgets/support should be communicated clearly and discussed with people well in advance of any changes being introduced. Health and social care staff should consider the possibility of isolation or mental health crisis when changing packages and eligibility criteria and be able to arrange reassessments and signpost support services where needed.

Flexibility

Many research participants commented on the value of and need for flexibility for the effective use of SDS – particularly around budgets.

In the survey we asked people to respond to the statement “Lack of flexibility in how I can use my personal budget makes Self-directed Support more difficult for me”. Of the 29 respondents, 11 (38%) strongly agreed or agreed, ten (34%) disagreed or strongly disagreed, and eight (28%) stated that they were unsure.

Chart 23: “Lack of flexibility in how I can use my personal budget makes SDS more difficult” (Survey)



Interviewees expanded on this theme. For example, some people reported difficult experiences in obtaining suitably flexible assistance with day-to-day tasks. One blind participant was told that they could not have help with shopping, because that was outwith the purview of SDS. They also found shopping stressful if reliant on assistance from shop workers who they did not know and who were not fully trained in how to assist blind and partially sighted people. In practice, they use their PA hours for social engagement, in part, to shop; but this is not officially acknowledged in their outcomes plan. Blind and partially sighted peoples’ experiences of SDS are explored in more detail in a separate thematic report.[35]

Flexibility: The research suggests that some people in Scottish Borders may not be able to use SDS as flexibly as they should, which can negatively impact on quality of life and enjoyment of rights to independent living and equal participation in society. Ensuring universal access to flexible SDS will help reinforce the positive impact of support. This flexibility could be in how people are empowered and supported to use their SDS, but also relates to people’s ability to have ongoing conversations with social work professionals and adjust systems accordingly on a regular basis.

Access to Short Breaks

Short breaks were an important topic for many MSMC research participants in Scottish Borders – for SDS users and unpaid carers alike.[36] People who used SDS budgets to access short breaks described them as an essential way that individuals and families could benefit by having time and space to themselves, doing activities that they enjoyed. Using SDS to access short breaks was mentioned by several survey respondents as an important chance for people to recuperate and relax.

Access to Short Breaks: Flexible, regular access to short breaks should be strongly encouraged in Scottish Borders because it is an essential element of SDS that results in good personal outcomes for people who access social care, families and unpaid carers.

Travel Costs

Travel costs – for respondents, PAs and care staff – were repeatedly mentioned as a concern, especially for people living in more rural areas of Scottish Borders. This was not always linked directly to people’s SDS packages, but where people employed PAs, the time to travel by public transport to carry out activities was not always acknowledged in care plans. Some people also stated that their rural locations meant that there was limited or no available public transport, but travel costs were not included in their SDS budget.

Some respondents indicated that they would welcome more assistance from social work in accessing appropriate travel passes and in dealing with transport problems. Even in cases where decisions lie with the Department for Work and Pensions rather than local authorities, most people tended to reflect on transport issues and SDS without clearly delineating between the two parts of their experience of social support.

Interviewees raised issues around bus drivers who do not properly alert disabled people of their arrival (e.g. blind and partially sighted people), and a need for more staff training in that area. They also discussed the problems that infrequent bus services, inaccessible pavements, and a lack of controlled crossings caused for disabled people trying to access public transport. People suggested that more should be done to ensure that services are both suitable and fully accessible for disabled people and people living with long term conditions. Some interviewees, particularly those who lived in more rural parts of Scottish Borders, stated that they rely upon the use of their PAs’ cars for travel, even for short journeys (e.g. to local shops). This requirement for PAs to drive can limit recruitment options.

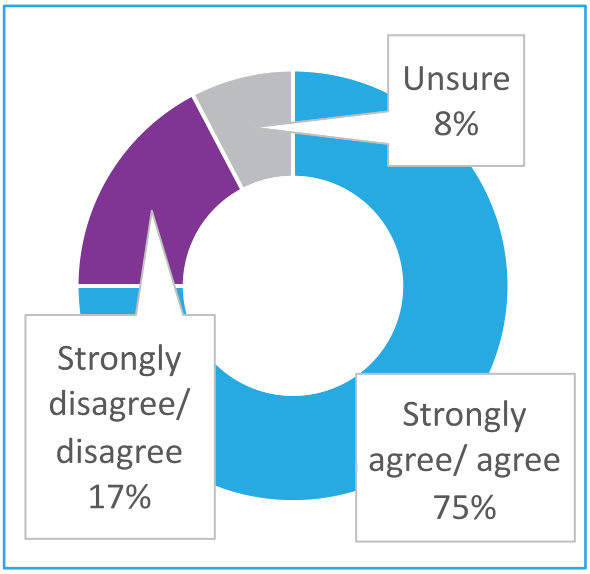
Travel Costs: People – particularly those living in more rural areas of Scottish Borders and those who are blind or partially sighted – require more acknowledgement and accommodation of travel costs in their SDS budgets. Some would also welcome assistance from social workers and third sector organisations in navigating the bureaucratic processes to obtain mobility vehicles and travel passes.

Communication and Relationships with Social Work

Good Conversations and Consistent Relationships

The importance of productive conversations in arranging appropriate social care support was highlighted in the 2019 Care Inspectorate thematic review of SDS.[37] As such, we asked survey respondents to rate how happy they were with the conversations they had about their support with professionals (e.g. social workers/ social work assistants, occupational therapists).

Chart 24: "How happy are you with the conversations you have had about your support with professionals?" (Survey)



Of the 52 respondents, 39 (75%) were happy or very happy, nine (17%) were very unhappy or unhappy, and four (8%) didn't know. Respondents in Scottish Borders were notably more satisfied with their conversations with professionals compared to people in other parts of Scotland.[38]

Interviewees highlighted that good conversations require effective communication, access to information, prompt decisions, and good future planning. People highlighted that they appreciated being able to both call and email their social worker and receive a prompt response – not just when they had questions about their support package, but about their wellbeing more generally. One interviewee said that after a period of stress, they contacted their social worker for pastoral support. They stated that:

> *"I felt a bit, oh gosh, I need to keep my social worker informed on what's going on. And then [they] went 'That's OK, that's what I'm here for. I'm here to be kept up to date on what's happening in the world of [interviewee name]'."*

The interviewee highlighted that this supportive response was helpful and was part of the trusting relationship they had built up with their social worker.

Many participants in Scottish Borders commended the assistance and efforts of proactive social workers, including those who signposted them to local services provided by third sector organisations (paid for through SDS). One interviewee spoke about the importance of empathy and practical assistance from their social worker. They highlighted how the social worker offered additional support with interviewing care workers, and summarised their positive experience as follows:

> *"[They] grasped immediately how difficult it was for me and how difficult it was for [Name]. Because [Name] has the problem of wanting everything to be rigidly organised […] and I needed rest at that time, I was so exhausted and so emotionally […] at my end of my tether, and [the social worker] just realised that was how hard it was. And [they] personally found the right carer to come and […] personally interviewed […] the carers' organisation that managed them. […] And [they] personally went to the manager to say, 'I need someone special to do [Name's] care because not just everyone can manage'. And [the social worker] found just the perfect person."*

Survey respondents who were happy with their conversations with social work professionals highlighted the importance of social workers having a breadth and depth of knowledge about SDS and local services. They also praised the listening skills and empathy of their social workers as key to their positive interactions, along with social workers having the time to listen to them and become familiar with their needs:

> *“They understood urgent need.”*

> *“The social worker took their time and listened to us.”*

> *“The social worker I spoke with was really helpful and understanding.”*

> *“My concerns were listened to and very helpful results were given by friendly caring people.”*

> *“The professionals involved took the time to listen and understand our personal circumstances.”*

People repeatedly referenced prompt communication and easy access to information as key to smooth communication with social work and effective SDS provision. Respondents also appreciated short waiting times for a response or decision from social work.

Another interviewee stated that they felt comfortable during their last review, because they felt that their social worker was focused on ensuring that their needs were met and appropriate changes were made around the introduction of free personal care. The interviewee said that their needs and outcomes were the focus of the review, rather than attempts to reduce their support package.

Consistency of social workers was viewed as a positive factor, as it gave people time to build up trust and awareness of people’s needs and individual situations. Social workers being able to take time to get to know people also facilitated flexibility of support arrangements – and that it could be difficult and time consuming to build trust. One interviewee reflected on how having the same social worker for reviews and follow-up assessments helped with their experiences of SDS. They stated that:

> *“We had a lovely [person]. […] [They] came out and […] did the initial assessment of [Name], and then […] came back later on to see how things were going on, that’s right. […] [The next follow up visit] wasn’t that long after. And [they were] particularly nice […], really efficient.”*

A different interviewee stated that they felt “very lucky” to have had the same social worker for over a decade, and reflected that consistency made a difference in enabling them to build a trusting relationship.

Good Conversations and Consistent Relationships: The research demonstrates that people in Scottish Borders generally feel that they have good conversations with their social workers. This positive finding supports the vital importance of good conversations and communication between service users and social work professionals – and there are many different elements and examples of this in the experiences shared by participants. It is important that social workers have a good breadth and depth of knowledge about SDS and local services, can demonstrate good listening skills and empathy, and take time to listen to people and become familiar with their requirements. These findings also highlight the benefits of consistent and trusting relationships with social workers, including having direct and varied lines of prompt communication available. Overall, we would recommend that work to ensure positive conversations and relationships should continue, with ongoing planning to guarantee high quality practice for all people using SDS.

Poor Communication and Relationships

A minority of participants described less positive experiences of communication and relationships with social work professionals in Scottish Borders. Of the 52 people who answered the survey questions about how happy they are with the conversations they have had about their support with professionals, nine (17%) indicated they were either very unhappy or unhappy. Some stated that their social worker did not have enough time or knowledge to meet with them and discuss their needs and questions properly. Others indicated more fraught relationships.

The most common reasons for dissatisfaction were that people “did not feel listened to”, experienced frequent changes of social workers, and/or felt they had received inadequate information about SDS. Key comments from people who were unhappy with their conversations and relationships with social work professionals are as follows:

> *“Very uninformative, no answers to questions, not very well explained so we still don’t know what [SDS] really is or how it functions. It also means we can’t figure out a suitable care plan so my partner can return to work… I felt very misunderstood with my condition and needs.”*

> *“No named person had been in touch since money was awarded three years ago! We currently don’t have a named social worker.”*

> *“I have never had a conversation about SDS – the first I heard about it was when I received this survey. So I called the number provided [on the MSMC survey] to find out what it was about!”*

Some respondents highlighted that while they were happy with their face-to-face meetings with social work, “too many conversations were on the telephone after the initial visit.” Others reported that while their social workers were helpful, they nevertheless faced assumptions that family and friends were happy and able to provide unpaid care – even when the participants would have preferred to employ paid carers.

Several research participants raised issues about problems of accessible communication with social work. One interviewee requested access to their files from social work and found the language that their social worker used to describe them deeply offensive. They summarised the situation as follows:

> *"This person [social worker] who came [...] said, 'No, that's not right [...] you can't have that, it's not paid for anymore.' [...] And [they] wrote [...] 'This couple [...] have become too dependent on the carers.' Well we are dependent on the carers, because without them I couldn't manage to do all the things that I do with my spouse."*

The interviewee provided specific examples of derogatory language used to describe them in reports, which has not been quoted directly to preserve participant anonymity.

Another interviewee stated that they would have benefited from clearer information about what to expect in advance of their last needs assessment – including who would be present, what questions they would be asked, and what tasks they would be expected to carry out (e.g. preparing food, accessing the bathroom). As it was, they stated that the social work professionals "weren't upfront about what they were doing", and the surprise nature of the assessment process carried out by a social worker and occupational therapist made it feel like a "two-pronged attack".

Several research participants stated that they would welcome more empathy and respect during their interactions with social work, and some discussed the limitations of available feedback and complaint options. People also indicated that they wanted to be informed promptly if their named social worker changed, and that they should be able to request to speak to a different social work professional if trust breaks down.

Finally, one survey respondent recounted how following an operation in a private hospital, the "liaison between the private hospital and social work was bad/inconsistent", and that people would benefit from greater streamlining of services around integrated care.

Poor Communication and Relationships: Examples of poor communication raise clear concerns about decision making and autonomy; if information about SDS is not provided, or people do not have accessible documentation about their options, then they cannot be said to control or choose their support. The findings invite further work to expand existing good practice in Scottish Borders to ensure that people's experiences of conversations and relationships with social work are consistently good. No-one should have to deal with discriminatory or judgemental language, attitudes or behaviour from social work professionals and people must be treated with dignity and respect. Professionals should ensure that all unpaid carers are offered carers assessments and have their rights explained to them, and should not assume that family members and friends are able or suitable to provide unpaid care. Health and social work professionals should respect service users' preferences if they do not wish to be reliant on family members and friends for their care and support. All processes and paperwork should be transparent and shared in an accessible format with service users. Social work staff should proactively gather regular feedback – good and bad – from service users, families and unpaid carers as a way to support continuous improvement. People should be proactively informed on a regular basis about how they can challenge decisions, access independent advocacy and support, local authority complaints procedures and the independent oversight of the Scottish Public Services Ombudsman (SPSO).

Transparency

As indicated throughout this report, research participants commented on the importance of transparency in a variety of ways, centred around the need for clear information about what to expect from SDS and social workers, the process of accessing support, and how to challenge decisions.

While some people spoke warmly about transparency in Scottish Borders, others – particularly people with learning disabilities[39] and people who are blind or partially sighted – expressed concerns about transparency of processes that were often synonymous with inaccessible information. One person stated that they had requested assistance with accessible paperwork and struggled to get assistance from social work. This made them nervous about signing a care provider contract under SDS. People with learning disabilities' experiences of SDS are explored in more detail in a separate thematic report.[40]

Another interviewee shared that when it came to receiving a needs assessment, they "had to really push them to even get to the assessment stage itself." They were initially informed by social work that they were not eligible for a needs assessment. The interviewee challenged this decision and was then granted a needs assessment and was subsequently able to access SDS. They highlighted that greater transparency around pre-screening processes is necessary to ensure everyone has access to appropriate support.

Similarly, another participant outlined that they had been deemed ineligible for support, with little transparency about the decision making process. The interviewee felt strongly that they require additional support but was uncertain about how to challenge the decision. They had not been provided with information on how to access independent advocacy services.

Several respondents touched upon the lack of transparency during the needs assessment and that they lacked access to the calculation of need carried out by social work or to the eligibility criteria for support. People also reported that they would like access to copies of all documentation concerning their social care provision, including copies of their agreed budget and personal outcome plans, but struggled to obtain these documents from social work.

Transparency: The research indicates that while there are good examples of transparent processes in Scottish Borders, this is not consistent across all areas and more work is needed to ensure systematic good practice and complete transparency across several elements of SDS/ social care. This includes publicly available information about eligibility criteria, needs assessments, budgets and support packages, changes to support, participation in decision making and how to challenge decisions. Further information on document publication dates, webpage timestamps, details of Equality Impact Assessments, and the role of people who use support, carers, and partner organisations in decision making, is encouraged.

Care Staff Recruitment, Training and Quality

Throughout MSMC, care staff – PAs, support workers, and agency staff alike – were mentioned as a key element of people's experiences of SDS and social care.

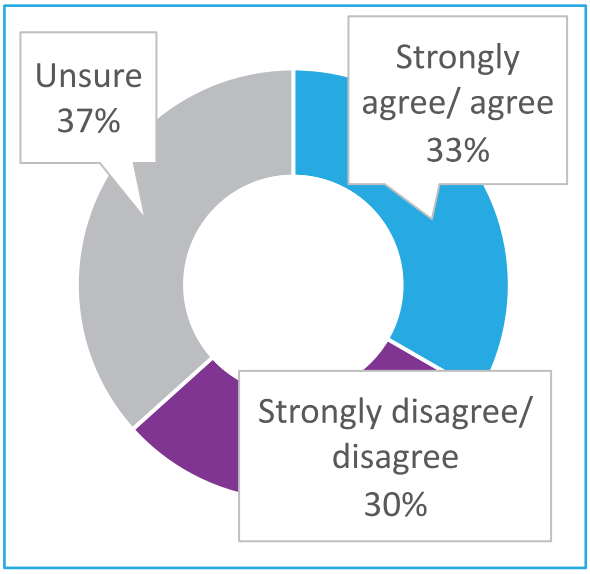
Several interviewees outlined how SDS has provided them with person centred support that benefits their entire household. One couple described how one partner's long term condition means they struggle to trust or relax around new or unfamiliar people. However, having a regular team of PAs enables the interviewees to pursue separate interests, enjoy short breaks, and have a higher quality of life. The benefits of having a trusted team of PAs or support workers was a key theme for several participants in Scottish Borders.

People in Scottish Borders commented that care staff travel and training costs (e.g. specialist first aid or medical training required for them to carry out their job appropriately) should be included in their SDS budgets. They felt that this would help ensure a quality care workforce (including PAs) in each local area, including for people living in more rural locations.

Staff Recruitment, Retention and Turnover

In the survey, we asked people to respond to the statement "Lack of a regular personal assistant makes SDS difficult for me". Of the 30 respondents in Scottish Borders, ten (33%) strongly agreed or agreed, nine (30%) disagreed or strongly disagreed, and 11 (37%) were unsure.

Chart 25: "Lack of a regular personal assistant (PA) makes SDS difficult for me" (Survey)



These findings are supported by comments made by interviewees about the importance of, and difficulties in finding and retaining, PAs who are appropriate to their requirements. Several interviewees commented on concerns with PA recruitment, specifically linked to their experiences using Option 1 in Scottish Borders, and their responsibilities as employers. Interviewees discussed the volume of forms they were required to process, the complexities of employing PAs, and their uncertainty about legally binding contracts.

One interviewee who uses Option 1 shared the challenges they had in arranging PA cover. On the one hand, they appreciated being able to employ people and set their working hours, stating "that is the beauty of the system, it allows flexibility". However, they also shared that they would like to be able to call on agency staff in an emergency, so that "if the flexibility broke down for whatever reason, that there was a standby. Something that was there, in case of emergencies." However, most interviewees using Option 1 enjoyed the flexibility with personal recruitment of PAs rather than agency staff, and the ability to have greater choice over their support.

A different interviewee outlined the important role that PAs play in their everyday life. They explained that for them, "it's not just the day-to-day support that [PAs] offer. They offer the emotional support as well." Another interviewee shared that they find unfamiliar faces and new people unsettling, so their social worker agreed they could employ a family member as a PA. They appreciated the understanding shown by their social work department.

An interviewee who had a good relationship with a trusted team of carers who had supported them over several years, reflected on their experience:

> *"I think that's the advantage of having carers long term, that they've been able to adapt as my condition has worsened."*

Several interviewees mentioned they had received support from Encompass in arranging their care. Some respondents suggested they would welcome more support from Scottish Borders Council to arrange PA training and continued professional development.

Care Workers and Risk

Several people commented on their consciousness of the potential risks of being reliant on care workers – even those who currently had good working relationships with trusted people.

One respondent discussed their feelings of vulnerability around support staff who provide personal care on a one-to-one basis – and vice versa:

> *"Even to the support staff who come in, we can be vulnerable to them. Even though we know them, we've known them for five years, but even at that we can still be vulnerable to them. And likewise, they can be vulnerable to us."*

The interviewee went on to state that sometimes support workers can build up good, trusting relationships with service users, but this can create different problems with boundaries – even with good intentions:

> *"And staff forget. And how I say that is because one of them has offered to give me a cuddle. And I'm thinking, 'in your professional role that is not allowed because I'm not allowed to touch you.' […] I did say to my support staff, 'the only person that gets to do that is my mum.' And [they] went, 'that's the best cuddle that you can ever receive.'"*

While the interviewee appropriately diffused this situation, they recounted this experience within a wider context – particularly of being aware of other people's discomfort at their sexual orientation. It was evident that while the interviewee had a team with whom they were comfortable, they found that trust was particularly important for them, having experienced discriminatory attitudes elsewhere in their community. It is worth noting that they stated their social worker was excellent in providing additional support in this area.

Care Staff Recruitment, Training and Quality: Some people would welcome more support with PA recruitment, training and continued professional development. Scottish Borders should work with people who access SDS and unpaid carers to improve systems and processes related to care staff recruitment, training and quality. It is also evident that some people would welcome improved access to suitably trained and high calibre care workers. While some people are comfortable with the role of employer and have experienced good, long term, working relationships with their support workers, this experience is not universal. This suggests that staff in Scottish Borders should continue to work with people accessing SDS/ social care to find ways to improve systems and processes – particularly around difficulties with recruitment, training, and staff retention within the wider social care sector. This support and acknowledgement of variable practice is particularly important when social care and social work professionals are discussing care arrangements with people who have had poor experiences in the past. People have the right to feel safe – particularly in their own homes – and social care workers and professionals across the sector should do all they can to support service users to feel safe, secure, and independent.

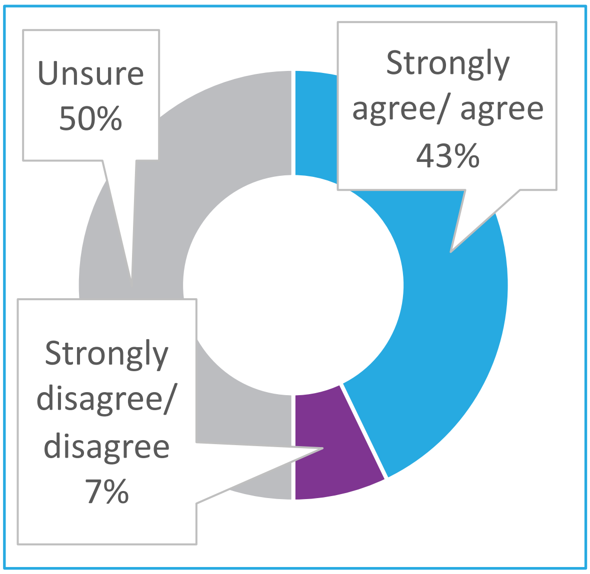
Independent Advocacy and Support

Respondents in Scottish Borders accessed independent advice and advocacy services for a range of different reasons. These included access to information, access to needs assessment criteria, assistance to develop a support plan, exploring flexibility with SDS budgets, mediation with social workers, support to appeal a decision, and advice on payroll and other PA employer related issues. Survey respondents spoke positively of the benefits of independent advocacy and independent advice and support organisations in Scottish Borders.

Independent Advocacy

We asked survey participants to respond to the statement "access to independent advocacy makes SDS easier for me". Of the 28 respondents, 12 (43%) strongly agreed or agreed, two (7%) disagreed or strongly disagreed, and 14 (50%) were unsure.

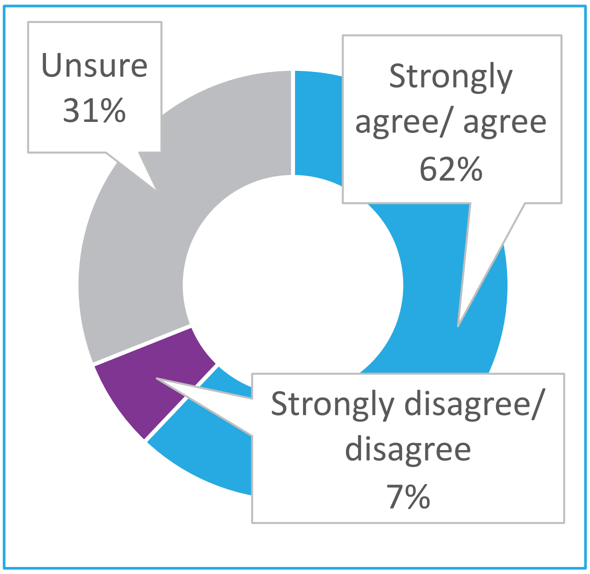
Chart 26: "Access to independent advocacy makes SDS easier for me" (Survey)



Independent Advice and Support

When asked whether access to independent information and support made SDS easier for them, people responded in a positive fashion. Of the 29 respondents, 18 (62%) strongly agreed or agreed, two (7%) disagreed or strongly disagreed, and nine (31%) were unsure.

Chart 27: "Access to independent information and support makes SDS easier for me" (Survey)



Survey respondents and interviewees commented on the value of independent advice and support in accessing SDS. Several people highlighted that they had benefited from the involvement of independent advice and support services during their needs assessment and reviews, and others had first heard about SDS via Encompass or other organisations.

Respondents drew upon independent advice and support organisations for support on a range of different issues. Specific examples include discussing the potential introduction of pre-payment cards for people using Option 1, increasing accessibility to public transport links, and gaining health condition specific information.

Peer Support

Several people in Scottish Borders highlighted the value of peer support and encouraged the promotion or establishment of local peer networks. According to some participants, peer support helps to sound out ideas around how support could be arranged, facilitates access to information, combats isolation, and prompts some people to be SDS ambassadors. Other people referenced the Scottish Borders SDS Forum as helpful in connecting them to other people with lived experience, and in campaigning for better conditions and access to services.

Independent Advocacy and Support: People clearly value and benefit from independent advocacy, advice and support, and these services play an important role in SDS/ social care. Scottish Borders Council's partnership working with Encompass was mentioned by several respondents as a helpful part of their engagement with SDS and social care. As well as ensuring that these services continue to be sufficiently resourced to carry out their vital work, we recommend that social work and healthcare professionals be given more training and information about local independent advice, support and advocacy organisations so they can routinely refer people and recognise the value they bring to their own work. Focused efforts are required to ensure all people are aware of – and can access – independent services. Local peer support networks and groups such as the Scottish Borders SDS Forum should also be encouraged and supported.

Response from Scottish Borders Council

We are very pleased to have had the opportunity to be involved in this research and to have this valuable information from the 71 people in the Scottish Borders who contributed their experience of SDS either through interview or survey.

It is heartening to know that most people reported a positive experience, and examples were given of good conversations and relationships with social work staff, and of people participating in decisions about their support. And to know that overall SDS had improved people's social care experience.

Scottish Borders has promoted and developed a community led "good conversations" approach to focus on the issues that matter to individuals, and work with the third sector and community groups to facilitate a holistic approach to social care. At the time of the research there were 14 "What Matters" hubs and various "pop up" hubs across the Borders in community venues.[41] These localised multi-organisational hubs provide information and link people to resources available in the community and to more formal resources, as required. We are now rolling these out as virtual online hubs and will offer these within community spaces when appropriate.

Some respondents were unsure of, or feel that they had not been made aware of all four options. We want people to know their choices, although are very aware there are certain challenges to being able to offer the full choice and flexibility that people should have. We have areas where there is only one (very stretched) provider, and areas where it is difficult to recruit staff to work either as a personal assistant (PA) or to an agency. In providing good information we need to ensure that people know the options, we are upfront about the challenges, and together we address these. An important area for development, which we are progressing, is partnering with the third sector and communities to co-produce formal and informal support solutions.

The report is timely as we are developing a staff training programme, along with Encompass, the local support organisation, to ensure staff and people using social care support are well informed. This is supported by their SiRD project which also offers pre-assessment information to people. We are also working with the local SDS Forum to produce more detailed information for people where gaps have been highlighted.

A participation request has concluded with agreement to a proposal to offer the option of prepaid cards; this involved SDSS, the SDS Forum, Encompass and the Carers Centre.

Encouraging flexible, regular access to respite is recommended in the report. We have a pathway specifically for carers to access information and support through our local Carers Centre. We have seen a significant increase in the uptake of replacement care since the Carers Act, with option one being the preferred option. The last year has been particularly difficult for many carers and we have targeted funding to support carers and co-design a variety of options.

We are keen to review the findings and recommendations with stakeholders. Research participants have raised some concerns and we want to address these, build on the good practice recognised in the report and jointly plan improvements. With the introduction of the SDS Standards there is also a useful opportunity to include the research as we review our approach against these new standards.[42]

For more information from Scottish Borders Council please contact them directly at: **socialworkconsultation@scotborders.gov.uk**.

Endnotes

1 To support readability, the 'N' number is not reported for all survey question responses. Due to the relatively small number of interviewees being discussed in this report (11 interviews, spanning 13 people's experiences of SDS), we use "some" or "several" to refer to three or four interviewees, "many" to refer to five or six interviewees, and "the majority" to refer to seven or more interviewees.

2 Information and documents related to project design and methodology can be found in the national report, available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/. All MSMC reports are also published on the Self Directed Support Scotland website, available at: https://www.sdsscotland.org.uk/mysupportmychoice/.

3 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice - People's Experiences of Self-directed Support and Social Care in Scotland - National Report* (Oct 2020); *Women's Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *People with Mental Health Problems' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); P*eople with Learning Disabilities' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Blind and Partially Sighted Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Black and Minority Ethnic Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020). These reports, and an Easy Read version of the national report, are available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

4 As well as the work of the Care Inspectorate and Audit Scotland noted in the MSMC national report, we note the recent Independent Review of Adult Social Care. See https://www.gov.scot/groups/independent-review-of-adult-social-care/ and https://www.alliance-scotland.org.uk/blog/resources/independent-review-of-adult-social-care-in-scotland-engagement-report/.

5 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice - People's Experiences of Self-directed Support and Social Care in Scotland - National Report* (Oct 2020); *Women's Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *People with Mental Health Problems' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); P*eople with Learning Disabilities' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Blind and Partially Sighted Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020); *Black and Minority Ethnic Peoples' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020). These reports are available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

6 Scottish Government, *Self-directed Support: A National Strategy for Scotland* (2010). Available at: http://www.gov.scot/Resource/Doc/329971/0106962.pdf.

7 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice - People's Experiences of Self-directed Support and Social Care in Scotland - National Report* (Oct 2020). Available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

8 NRS Scotland, “Scottish Borders Council Area Profile”. Available at: https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/scottish-borders-council-profile.html#household_estimates.

9 Scottish Borders Council, “What is SDS?”. Available at: https://www.scotborders.gov.uk/info/20055/adults_and_older_people/371/self_directed_support.

10 Scottish Borders Health and Social Care Partnership, *Changing health and social care for you: strategic plan 20-16-2019* (2016). Available at: https://www.nhsborders.scot.nhs.uk/media/382187/HealthandSocialStrategicPlanFEB16.pdf

11 Scottish Borders Council, “Introduction to Social Care”. Available at: https://www.scotborders.gov.uk/download/downloads/id/5505/introduction_to_social_care.pdf.

12 Scottish Borders Council, “Preparing for Assessment”. Available at: https://www.scotborders.gov.uk/download/downloads/id/5506/preparing_for_assessment.pdf.

13 Encompass. More information available at: https://www.encompassborders.com/.

14 Scottish Government, *Self-directed Support: Practitioners Guidance* (2014), Available at: https://www.gov.scot/publications/self-directed-support-practitioners-guidance/pages/6/

15 Scottish Borders Council, “Assessing if you are eligible for a service”. Available at: https://www.scotborders.gov.uk/info/20069/how_do_i_get_a_service/511/eligibility_criteria.

16 *Ibid*.

17 Information Services Division (now Public Health Scotland), *Insights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018* (11 June 2019). Available at: https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/index.asp?#2399. More recent data is also available from PHS, published after MSMC analysis was complete. Further information is available at: https://beta.isdscotland.org/find-publications-and-data/health-and-social-care/social-and-community-care/insights-in-social-care-statistics-for-scotland/.

18 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/. These figures do not include people accessing community alarms or telecare.

19 While it is common practice to exclude response groups of less than five for statistical and anonymity purposes, in this report we have not done so, while maintaining anonymity. To do otherwise would be to exclude some respondents, which would be problematic. Throughout this report, we indicate the number of respondents to each question to underline that recommendations are based on the experiences reported.

20 National Records of Scotland, “Scottish Borders Council Area Profile”. Available at: https://www.nrscotland.gov.uk/files/statistics/council-area-data-sheets/scottish-borders-council-profile.html#household_estimates.

21 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

22 Scotland’s Census (2011), “Ethnicity, Identity, Language and Religion”. Available at: https://www.scotlandscensus.gov.uk/.

23 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

24 This was a multiple choice question and some respondents chose more than one option.

25 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

26 Scotland's Census (2011), "Ethnicity, identity, Language and Religion". Available at: https://www.scotlandscensus.gov.uk/.

27 Scottish Government, *Poverty and income inequality in Scotland: 2015-2018* (2018), p. 10. Available at: https://www.gov.scot/publications/poverty-income-inequalityscotland-2015-18/pages/10/.

28 *Ibid*., p. 1.

29 *Ibid*., p. 12.

30 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

31 Information Services Division (now Public Health Scotland), I*nsights into Social Care in Scotland: Support provided or funded by health and social care partnerships in Scotland 2017/2018* (11 June 2019). Available at: https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/index.asp?#2399/.

32 *Ibid*., pp. 6, 48-60.

33 Public Health Scotland, Social Care Information Dashboard: https://scotland.shinyapps.io/nhs-social-care/.

34 In the national MSMC report, 84% of survey respondents reported that they were on their preferred option, with 9% unsure and 7% not on their preferred option.

35 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice: Blind and Partially Sighted People's Experiences of Self-directed Support in Scotland – Thematic Report* (Dec 2020). Available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

36 As a term that is still widely used, some MSMC respondents referred to "respite". We use "short breaks" in place of "respite" in this report, following discussion elsewhere by unpaid carers and carer organisations about the unhelpful definition of respite as "a short period of rest from something unpleasant". For example: www.collinsdictionary.com/dictionary/english/respite.

37 Care Inspectorate, *Thematic review of self-directed support in Scotland: Transforming lives* (2019). Available at: https://hub.careinspectorate.com/media/3676/thematic-review-of-self-directed-support-in-scotland-transforming-lives.pdf.

38 As demonstrated in the MSMC national report, of the 434 respondents overall, 242 (56%) were happy or very happy, 135 (31%) were very unhappy or unhappy, and 57 (13%) didn't know.

39 SDSS and the ALLIANCE endorse the use of the term "learning difficulty" in preference to "learning disability", in order to highlight that it is society that disables people with impairments, rather than that people possess intrinsic "disabilities" (this is the basis of the social model of disability). In MSMC reports, however, the more traditional term, which is still in standard use by public bodies and more common in public discourse, is used. This choice was made for practical reasons, to maximise understanding of the survey language among the people surveyed and to allow comparisons to be made with other available data.

40 Health and Social Care Alliance Scotland and Self Directed Support Scotland, *My Support My Choice: People with Learning Disabilities' Experiences of Self-directed Support and Social Care in Scotland - Thematic Report* (Dec 2020). Available at: https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/.

41 Scottish Borders Council, "What Matters Hubs: COVID-19 Response". Available at: https://www.scotborders.gov.uk/info/20069/what_help_and_support_is_available/839/what_matters_hubs.

42 Social Work Scotland, "Self-directed Support: Framework of Standards, including practice statements and core components" (24 March 2021). Available at: https://www.gov.scot/publications/self-directed-support-framework-standards-including-practice-statements-core-components/.

Glossary

Budget / Hours / Package

The agreed support provision for an individual from the local authority or health and social care partnership.

Charging Policy

Local authorities decide on a charging policy for their services. Charging policy sits within a framework designed by COSLA that aims to maintain local accountability and discretion while encouraging local authorities to demonstrate that in arriving at charges, they have followed best practice.

COSLA

The Convention of Scottish Local Authorities (COSLA) represents local government in Scotland and the 32 local authorities. They work with councils to improve local services and processes.

Direct Payment

See “Option 1”.

Disability

The loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers. A disabled person is a person who experiences disability. Disability is the result of negative interactions that take place between a disabled person and her or his social environment.

Eligibility Criteria

Scotland’s National Eligibility Framework uses four ‘risk’ criteria to assess an individual’s requirement for SDS/ social care, categorised as critical, substantial, moderate, and low.

Guardian

An Attorney or Guardian Person can consent on behalf of someone if they lack decision making capacity. The local authority would have to conclude, in its assessment, that the person with assessed need has, after every attempt to support them, no capacity to decide to receive SDS.

Health and Social Care Partnership / HSCP

There are 31 health and social care partnerships in Scotland. They work towards a set of national health and wellbeing outcomes and are responsible for adult social care, adult primary health care and unscheduled adult hospital care. Some are also responsible for children’s services, homelessness and criminal justice social work.

Independent Advocacy Service/ Independent Advocate

Independent advocacy is a way to help people have a stronger voice and to have as much control as possible over their own lives. Independent advocacy organisations are separate from organisations that provide other types of services or support. An independent advocate will not make decisions on behalf of the person/group they are supporting. The independent advocate helps the person/group to get the information they need to make real choices about their circumstances and supports the person/group to put their choices across to others. An independent advocate may speak on behalf of people who are unable to do so for themselves.

Independent Living

Independent living means all disabled people and people living with long term conditions having the same freedom, dignity, choice and control as other citizens at home, at work and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.

Independent Living Fund / ILF

A Scottish Government fund available to certain people to enable them to live at home.

Independent Support Organisation

An organisation that provides independent, impartial information and support for people, for example on social care choices, e.g. a centre for independent living.

Integration Joint Board / IJB

Legislation in Scotland requires local authorities and NHS Boards to jointly plan and lead health and social care services. Two ways of doing this were provided – the ‘body corporate’ model (IJB) and the ‘lead agency’ model. 30 areas have adopted the IJB model (Clackmannanshire and Stirling formed a joint IJB, and Highland adopted the ‘lead agency’ model).

Impairment

An injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physiological or psychological function.

Local Authority / LA

Local council (32 across Scotland).

Needs Assessment

Review of individual’s support provision or plan by local authority staff.

Option 1 (also called “direct payment”)

After a support plan is agreed the money to fund it is paid directly to the individual, into a bank account managed separately from any other accounts they have. They can manage the money themselves, or with assistance from others. A record must be kept of how the money is spent. People may choose to use their direct payment to employ their own staff, purchase services (from agencies or local authorities), and/or purchase equipment.

Option 2

If individuals do not wish to manage their support directly, then local authorities can arrange to pay for support. People will still choose what support they want and how it will be provided, but the local authority (or another nominated organisation) will manage it for them.

Option 3

People can ask for their support to be arranged for them by the local authority and provided either directly by local authority staff or by someone else on behalf of the local authority.

Option 4

A combination of the other options – for example, it allows people to let the local authority manage some parts of their support package, while giving the individual direct control of other elements of their support. The money to fund the parts of the support which individuals will manage will be paid into a bank account in the same way as described in the direct payments option.

Occupational Therapist / OT

Occupational therapists provide support to people whose health prevents them doing the activities that matter to them.

Personal Assistant / PA / Support Worker

Someone who is paid to provide people with social care and support. They can be employed directly by the person or they can be arranged through an agency.

Personalisation

SDS is often described as the personalisation of health and social care. Personalisation means that people are actively involved in shaping and selecting the services they receive. However, services can be personalised without people using SDS to get them.

Physical Impairment / Physical Disability

SDSS and the ALLIANCE endorse the use of the phrase “physical impairment” in preference to “physical disability”, in order to highlight that it is society that disables people with impairments, rather than that people possess intrinsic “disabilities” (this is the basis of the social model of disability). In this report, however, the more traditional terms, which are still in standard use by government agencies and more common in public discourse, are used. This choice was made for practical reasons, to maximise understanding of the survey language among the people surveyed and to allow comparisons to be made with other available data.

Reablement

A short-term social care rehabilitation service to assist people to become or remain independent in doing everyday tasks (typically after hospital discharge).

Self-directed Support / SDS

Self-directed Support is about how a support plan is put into action so that people receive the help they need to meet agreed personal outcomes. It means that people have choices in how their care and support is managed. By choosing one of four options people can choose how best to manage their support based on their individual needs.

Short Breaks

A pause from routine care arrangements (also referred to as “respite”). Could include holidays or short breaks for the person who receives support (with or without their PA/carers), and/or a pause from caring responsibilities for carers. May also include day activities.

Sleepovers

The provision of care and support services overnight.

Social Care

Social care includes all forms of personal and practical support for people who need extra support. It describes services and other types of help, including residential care homes, care at home, and community alarms/telecare systems, and systems designed to support unpaid carers in their caring role/s.

Support Plan

A support plan says how people will spend their budget to get the life they want, agreed between the individuals involved and the local authority.

Support Worker

See Personal Assistant / PA.

Unpaid Carer

Anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

About the Project Partners

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with indi-vidual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery part-ner and foster better cross-sector understanding and partnership.

Self Directed Support Scotland
the organisation of choice

About Self Directed Support Scotland

Self Directed Support Scotland is a national partner organisation that supports the implementation of SDS across all of Scotland. We do this by having other organisations join us so that we can work together at both a local and national level, to influence the implementation of SDS. SDS Scotland has a wide range of members organisations covering every Local Authority area in Scotland. We are particularly keen to support the development of organisations run by and for disabled people. Our members support over 31,000 people across Scotland with their social care choices. Together we work to ensure that SDS is implemented successfully so that people have full choice and control over their lives. We do this by:

- Supporting our members in the delivery of their services to provide local independent information, advice and support to those at each stage of their social care journey.
- Signposting individuals at each stage of their social care journey to appropriate organisations that can support them.
- Representing our members nationally to discuss SDS implementation.
- Showcasing good practice from those involved with SDS.
- Providing health and social care professionals, other voluntary organisations and educational institutions with the resources they need to champion SDS.
- Conducting research which recognises the power of lived experience.
- Developing and delivering training on a range of key topics relevant to SDS.

The ALLIANCE

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Self Directed Support Scotland
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